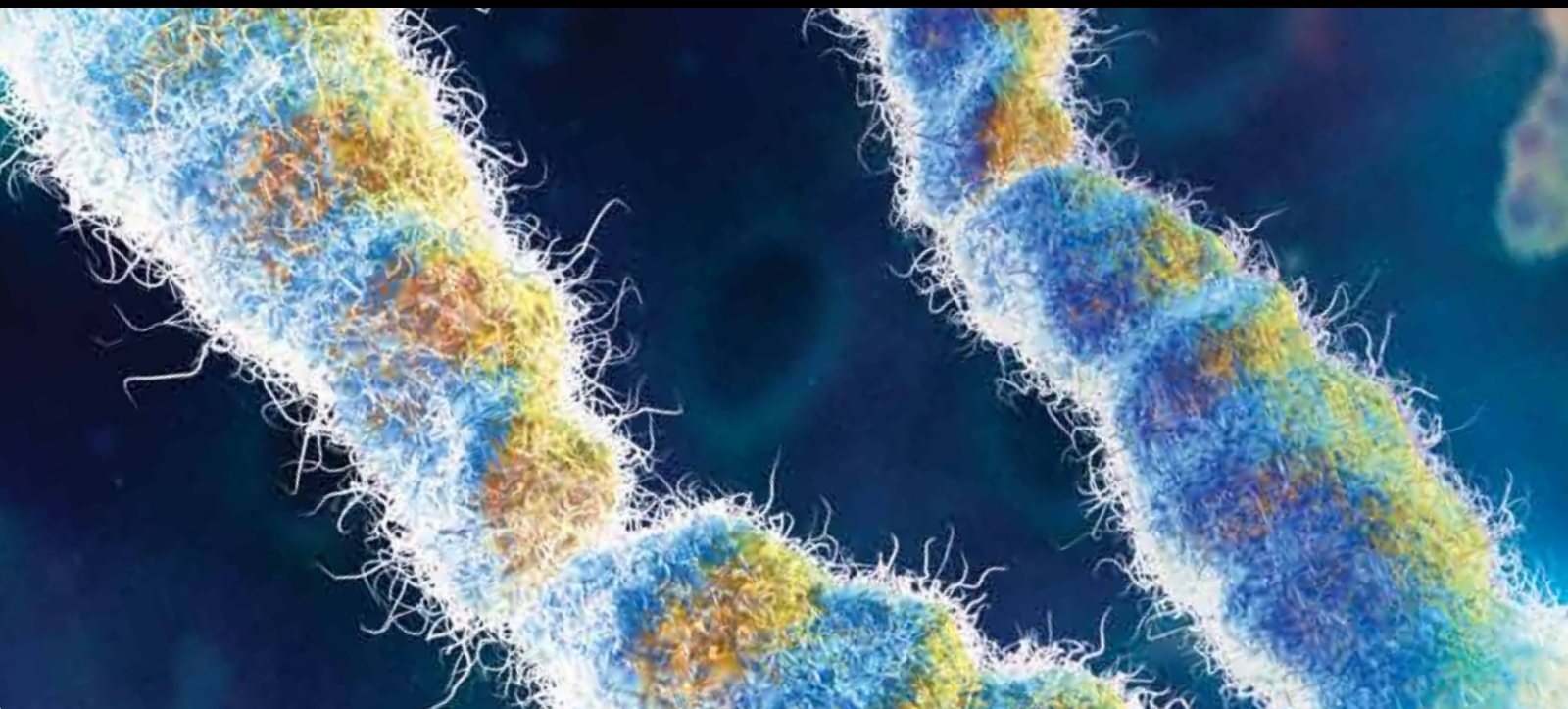


Aging in Place in Late Life: Theory, Methodology, and Intervention

Guest Editors: Agneta Malmgren Fänge, Frank Oswald, and Lindy Clemson





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and Lindy Clemson



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Editorial

Aging in Place in Late Life: Theory, Methodology, and Intervention

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This special issue focuses on aging in place in late life. Aging in place is about being able to continue living in one's own home or neighborhood and to adapt to changing needs and conditions. It is of high concern due to the increasing number of old and very old people in all societies and challenges researchers, practitioners, and policy makers in many societal and scientific areas and disciplines. We invited authors to contribute original research papers as well as conceptually driven review papers that would stimulate the continuing efforts to understand the different aspects of aging in place in late life. The papers that were submitted came from very diverse disciplines, such as sociology, psychology, occupational therapy, nursing, architecture, public planning, and social work. Given the number and diversity of papers submitted, we can conclude that aging in place is an important concern throughout the world and that different kinds of measures are taken to come up with local, national, and international solutions that enhance aging in place. It remains a very complex issue that needs and deserves to be investigated from many different perspectives and assessed by means of different methodological origin, covering qualitative and quantitative measures, as well as mixed-method approaches. Subsequently, the selection of papers presented in this issue only sheds light on some aspects of sociophysical person-environment exchange as people age, contributing to the ongoing discussion in the field of environmental gerontology.

Vasunilashorn et al. present a review study targeting the concept of aging in place as a research topic whose time has come. They found an increasing proportion of scientific

papers over time, in particular those focusing on policy matters and the use of technology to support ageing in place. They concluded that aging in place is far from a one-size-fits-all issue but rather something that differs across populations due to, for example, culture, demographic, and legal systems.

The perspectives of the older persons themselves on social relationships and connectedness, social exclusion and inclusion, and the impact of the neighborhood were targeted in the following studies. By way of qualitative interviews, in the study by Emlet et al., older people were asked about their perception of social connectedness, how the society can help with life transitions to support aging in place, and what kinds of difficulties that they perceived in the home and neighborhood. However, different in conceptual framing and method, similar topics were emphasized by Yen et al., as well as Burns et al. The studies revealed that older people staying in the same neighborhood may experience strangeness, social exclusion, economic exclusion and insecurity due to gentrification and had few positive social ties in the neighborhood. They had a strong drive to stay active and to have meaningful social interactions with others, and they also wanted to contribute to the society. However, they experienced considerable structural barriers, for example, access to transportation services and other services in the neighborhood that made it difficult to stay active and connected to the society. Continuing on the same theme, a survey paper by Wu et al. investigated social isolation among older people in Singapore, finding that the strongest predictors were living alone or living with children. Also pointing towards the importance of community and

social processes for aging in place the next paper by Galinsky et al. developed and tested a new measurement of collective efficacy feasible for use among older people. Collective efficacy refers to social processes on the level of person-neighborhood interactions, social cohesion, and informal social control, all known to be important for well-being in old age.

In contrast, indoor behavior may include various forms of person-environment relationships of more recent scientific interest. For instance, older adults with hoarding behaviors are often at risk of being evicted from their homes because they constitute a risk for other tenants' safety and security in the housing. For example, the risk of fire increases as does the sanitary risks of having a cluttered home. Thus, as Whitfield et al. pointed out in their paper, this group of people is at risk of being marginalized and to experience and rapidly declining health and well-being. The authors explored a collaborative community planning approach for finding solutions that could enhance the possibilities for aging in place. They found that, with structured collaboration between different actors in the communities, the professionals gained access to expertise from other staff and that such knowledge benefitted the community planning at large. The older people gained insight into their hoarding behavior, and they perceived that this approach fostered empowerment and minimized loneliness and isolation.

Yang and Sanford investigated the relationships between the environment, activity performance at home and community participation, and their potential for aging in place. Comparing older people with and without mobility limitations they found that persons with mobility limitations, experienced more environmental barriers in the home and the community than those without. They also found that environmental barriers in the home and the community explained travel and community participation among those with limited mobility. They reasoned that reducing environmental barriers in the home saves energy and the older person can thus be more active in the community.

The number of persons experiencing dementia "in place" is rising dramatically with increased age in the population. Their problems pose challenges to themselves but also to their close relatives and the society. Another study on aging in place with dementia by Beard et al. focused on couples where one partner had been diagnosed with dementia. In in-depth interviews, they expressed that they desired to go on as before and not to let the problems take over their lives. They strived to remain a couple and to invest as much energy as possible into a life where they worked together, developing a "joint career." Investigating the management of dementia home care resources by way of an ethnographic design, Ward-Griffin et al. found that care resource allocation was relying heavily on family care giving and that formal resources were used as a supplement, most often when the family situation was becoming serious. Family care givers and recipients found the care system difficult to navigate in and without flexibility for acute needs.

One of many interventional approaches to support aging in place in late life is to offer preventive home visits to older people living in the community, mostly above a certain age.

In some countries, it is mandatory for the municipalities to organize and conduct preventive home visits. The aim of the visit is to inform and identify current or potential risks to health, activity, and participation to be able to intervene before the problems occur. Different home visit protocols have been developed and applied in practice; however, the vast majority of them are not based on current evidence. In their study, Löfqvist et al. described the development and pilot testing of an evidence-based protocol for preventive home visits in Sweden. By way of reviewing scientific papers as well as conducting focus group interviews with older people, they identified key aspects important to include in the protocol. The protocol was then applied and tested for feasibility.

Finally, Jutkowitz et al. investigated post hoc the cost effectiveness of a home-based intervention targeting vulnerable older adults. The outcome was defined as life years saved. In the intervention group, the persons lived significantly longer, to additional costs for the intervention. Even though one can assume that the intervention group also may be healthier and consuming less health care resources, this remains to be investigated. To advance services and policies that support aging in place, economic analyses of programs are important. In this respect, the health economic approach used in the study offers a preliminary understanding of the costs of a highly effective intervention.

The variety in focus, theory, and methodology among the papers in this issue is a pleasing sign of the interest and effort being applied to aging in place issues by researchers and practitioners in diverse fields. Together and separately the papers have the potential to influence the societal debate as concern aging issues across the world and to inform decision makers in various fields about necessary measures to take in order to support aging in place in later life. We hope that the readers of this issue will find the papers interesting and inspiring for further research and debate.

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Research Article

Is Collective Efficacy Age Graded? The Development and Evaluation of a New Measure of Collective Efficacy for Older Adults

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Objectives. Community processes are key determinants of older adults' ability to age in place, but existing scales measuring these constructs may not provide accurate, unbiased measurements among older adults because they were designed with the concerns of child-rearing respondents in mind. This study examines the properties of a new theory-based measure of collective efficacy (CE) that accounts for the perspectives of older residents. **Methods.** Data come from the population-based Chicago Neighborhood Organization, Aging and Health study ($N = 1,151$), which surveyed adults aged 65 to 95. Using descriptive statistics, correlations, and factor analysis, we explored the acceptability, reliability, and validity of the new measure. **Results.** Principal component analysis indicated that the new scale measures a single latent factor. It had good internal consistency reliability, was highly correlated with the original scale, and was similarly associated with neighborhood exchange and disorder, self-rated health, mobility, and loneliness. The new scale also showed less age-differentiated nonresponse compared to the original scale. **Discussion.** The older adult CE scale has reliability and validity equivalent to that of the existing measure but benefits from a more developed theoretical grounding and reduced likelihood of age-related differential nonresponse.

1. Introduction

Evidence suggests that community processes are important to older adults' ability to age in place [1, 2]. Of the eight factors identified in the World Health Organization's report on age-friendly cities [3], three seem fundamentally dependent on community processes. These three, *Age-Friendly Outdoor Spaces* (WHO factor 1), *Social Participation* (WHO factor 4), and *Respect and Social Inclusion* (WHO factor 5) may all be supported by structural innovations and resource infusion, but, in all likelihood, cannot be sustained without ongoing community involvement. Community-level behavior is important not only for the immediate results produced by discrete actions and social exchange, but also for its role in shaping the perceptions and norms of behavior held by the community's residents.

The perceptions and norms of behavior likely relevant to the three WHO factors fall under the rubric of a well-developed sociological construct, *collective efficacy*. Collective efficacy (CE) refers to perceptions and norms of two categories of social processes that represent two kinds of community social resources: trust and connection, commonly referred to as social cohesion, and expectations for action, commonly referred to as informal social control. Studies have shown the importance of CE for multiple aspects of well-being among older adults [4–7]. In particular, CE has been shown to play a role in enhancing older adults' physical health and neighborhood satisfaction, which may predict their intentions to move and actual migration [2, 5, 8–14]. Unfortunately, existing scales measuring this construct may not be ideal for use with older adults because they were

designed with the concerns of child-rearing respondents in mind [15]. For example, scale items that ask about expectations of neighbor cooperation in monitoring children may be less relevant to adults whose children are grown. At the same time, the priorities of older adults are not necessarily reflected in these existing scales.

At the individual level, a number of scales measuring such constructs as anxiety and life satisfaction have been developed based on theory and evidence regarding the distinctiveness of older adults' experiences (e.g., [16–19]). These and similar scales are able to measure the constructs of interest among older adults more accurately and with less response bias because they take into account the unique concerns, challenges, and goals of adults in the later decades of their lives [20]. For example, scales that feature items that are more salient to older adults show increased instrument acceptability in the form of higher response rates and lower differential nonresponse [21]. Such scales, by providing more easily recognized and comprehended items, also reduce response burden [22]. By following the same principles, scales measuring neighborhood social processes can be designed such that they produce more accurate measurement among older adults.

In this study we describe and test a new measure of CE. This measure was developed specifically for use in older populations, taking into account the unique ways that people of their age and cohort interpret and respond to common environmental cues, and the particular cues that we hypothesized would be uniquely important to older adults. In the first part of this paper, we explain the theoretical framework guiding our identification of environmental cues for CE likely to be salient to older adults. In the second part of the paper, we test the new measure's instrument acceptability, dimensionality, reliability, and criterion validity in an older adult population. In the third part of the paper, we appraise the new measure's construct validity by examining its association with individual health-related outcomes. Our aim was to construct a scale that can be used in research on neighborhood social processes, the health of older adults, and other factors that relate to aging in place.

Our theoretical framework combines CE theory with a consideration of the particular challenges and opportunities of the older adult life stage. As alluded to above, CE theory attempts to explain the association between neighborhood structural factors, social processes, and individual-level outcomes by positing that the neighborhood processes of social cohesion and informal social control mediate the relationship between the structural factors and individual outcomes [23, 24]. For example, compositional socioeconomic status may impact social cohesion, which in turn affects self-rated health, asthma rates, and inflammatory marker levels by reducing stress and fear [4–7, 25]. CE is therefore likely to be a part of the societal system that supports healthy living, safeguards individuals against adverse health events, and thereby enables aging in place [26]. CE is related to, but distinct from, social network interaction and exchange and social and physical disorder. The first is concerned with norms and expectations, while the second and third refer to actual behavior and conditions.

A range of theories from the aging and life course literature provide us with a framework for generating a set of cues for social cohesion and informal social control that would be particularly salient to older adults [27–33]. A key focus of later life is to develop mechanisms to adapt to new challenges, including frailty and morbidity and decreased scope and density of social networks [30, 32, 34–37]. As applied to the CE framework, these perspectives suggest that perceptions of neighbors' willingness to assist older adults with tasks, and perceptions of neighborhood norms related to regulating behavior with the goal of enhancing neighborhood safety and traversability, will be particularly important. At the same time, older adults are not only concerned with compensating for losses and coping with challenges. Generativity is also a key component of later life, defined as helping the next generation by, for instance, passing on wisdom and thereby leaving a legacy [27–29]. Within the CE framework, this perspective incorporates the notion that intergenerational exchange may contribute to a prosocial orientation and a mutual respect for community contributions across the life course.

In the remainder of this section, we discuss the research literature underlying our selection of the four specific types of cues for CE that we believe would be particularly salient to older adults. The two types of social cohesion cues that we hypothesize to be particularly salient to older adults, based on theory in urban sociology and literature on aging, are those that relate to *active caretaking of vulnerable residents* and *age integration/lack of ageism*. The two types of informal social control cues that we hypothesize to be particularly salient to older adults, based on the theory and literature on aging, are those that relate to *minimizing social incivility* and *maximizing accessibility*.

Older adults may be particularly attuned to displays of solidarity in the form of social cohesion cues related to active caring and caretaking. Frailty and decreased mobility make some tasks that are easy in middle age significantly more difficult in later life [38, 39]. Simultaneously, many older adults experience a decrease in the scope and density of their social networks [40, 41]. As a result of this combination of changes, older adults are often more reliant on assistance from community members [42, 43]. Perceptions of the availability of neighbor assistance may be particularly important to the well-being of older women compared to older men and older single men compared to older married men, who are unlikely and unable, respectively, to rely on their spouses for help [44]. Older adults who believe that their neighbors will provide active caretaking may be more confident about their ability to stay in their homes. Our new measure of CE includes two items designed to capture the tendency toward active caretaking facet of the social cohesion construct.

Older adults may also be particularly attuned to, and able to benefit substantially from, social cohesion cues related to age integration and lack of ageism. Aging societies have experienced an increase in social separation of age groups, even as age heterogeneity within most neighborhoods has increased [45–48]. One reason for the persistence of social segregation by age despite decreased logistical barriers to socializing across age boundaries may be ageism, which may

interfere with communication across age lines [49]. Another factor impeding such communication is the decrease in information processing speed and loss of hearing that commonly occurs at older ages [50–52]. These factors combine to create a situation in which sustained effort is required for cross-generational socializing.

Perceptions of opportunities for cross-generational interactions are relevant to older adults' priorities, and ability to age in place, for a number of reasons. Communities in which older and younger people associate may be communities in which there are fewer age-based misunderstandings, biases, fears, and resentments, and greater empathy on the part of younger people for the challenges that come with later life [45, 48, 49, 53]. Older adults who perceive their communities as age integrated may therefore feel safer venturing outside to participate in community life, because they would have less reason to fear and more reason to feel connected to a wider range of their neighbors. Expectations of communication across age lines also encompass expectations for the ability to potentially pass on wisdom, neighborhood history, or practical advice and thereby feel and be useful [54]. Such opportunities for generativity are likely to be crucial to neighborhood satisfaction; being able to fill this social role has been associated with lower mortality [55]. Our new measure of CE includes three items designed to capture the age integration facet of the social cohesion construct.

Regarding the domain of informal social control, we expect that older adults pay increased attention to the community's expectations for behaviors that minimize social incivility, as a result of reverse ageism (prejudice of older people against younger people), the increase in frailty that often accompanies advancing age [48, 56]. Older people with impaired balance, reduced muscle strength, and limited gait speed may be more likely than spry younger adults to find the loud, unpredictable peregrinations of rowdy teenagers threatening [48]. Furthermore, as a result of reverse ageism, elderly residents may perceive even subdued teenagers as a threat [56]. Their perceptions of the neighborhood's expectations for protecting vulnerable residents from malicious young people may be particularly important for older residents' willingness to venture outside on a regular basis and for their neighborhood satisfaction. Our new measure of CE includes one item designed to capture the expectation for actions that minimize social incivility, a component of the informal social control construct.

Lastly, increased frailty and disability may also increase the salience of cues for informal social control in the form of expectations for behaviors that maximize accessibility. For many older adults, navigating their neighborhoods becomes more difficult as their mobility decreases and their vulnerability for adverse health outcomes resulting from interactions with environmental hazards increases [57–60]. Older frail adults may be more attuned to obstacles and hazards in the physical environment, particularly as those environments become dilapidated [61]. Increased expectations for actions aimed at improving the safety and integrity of the environment may be related to increased likelihood of maintaining and using physical abilities and competencies for two reasons: (1) it may be related to increased confidence about

venturing outside, and (2) it may relate to actual improved conditions [8, 61, 62]. Maintenance of the environment can in turn prevent the adverse health events that constitute barriers to aging in place [13, 14, 26]. Our new measure of CE includes two items designed to capture the expectations for actions that maximize accessibility, a component of the informal social control construct.

2. Methods

2.1. Data and Sample. We used data from the Chicago Neighborhood, Organization, Aging and Health study (NOAH). This study surveyed 1,500 adults aged 65 and over living in 80 selected Chicago neighborhood clusters. Each cluster was defined by two to three census tracts consisting of approximately 4,000 housing units. The sample frame consisted of all households in the city of Chicago containing at least one member 65 years of age or older. The weighted response rate for households with a phone number was 55.3% while the rate for those households for which a phone number could not be identified was 12.4%. The overall weighted response rate for the survey was 44.3%, a good rate for a telephone interview by contemporary standards [63, 64]. Interviews were conducted over the phone in English and Spanish between August 2006 and September 2007. The NOAH study was approved by the institutional review boards of both NORC and the Division of Biological Sciences at the University of Chicago. All participants provided verbal consent.

The sample consisted of the 76.7% of the 1,507 respondents with complete demographic, health, and community process data ($N = 1,151$). Descriptive statistics are shown in Table 1. The mean age was 73 (range 65–95), and 68% were female. Over two fifths (44%) were non-Hispanic White, over a third were Non-Hispanic Black (35.8%), and the rest were Hispanic (14.9%) or Other (5%). About a third (32.6%) were married, and about a tenth (9.8%) lived with someone under the age of 18. About a quarter had less than 12 years of education, about another quarter had graduated from high school, and a little under half had some college or more. A little more than a tenth of the sample had lived in their neighborhood for less than 10 years, while a little less than three quarters had lived in their neighborhood for more than 20 years. Those missing data, who were therefore excluded from the sample as described above, were more likely to be White Non-Hispanic than to be any other race/ethnicity combination.

2.2. Measures of CE. The CE questions were presented to the respondent in two blocks. The first block was introduced with the sentences, "Now I'm going to read some statements about things that people in your neighborhood may or may not do. For each of these statements, please tell me whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree." The second block was introduced with the sentence, "For each of the following, please tell me if it is very likely, somewhat likely, somewhat unlikely, or very unlikely that people in your neighborhood would act in the following manner."

TABLE 1: Descriptive statistics.

	%
Age (years)	
65–74	59.7
75–84	31.4
85–95	8.6
Sex	
Female	67.7
Male	32.3
Race/ethnicity	
White Non-Hispanic	44.0
Black Non-Hispanic	35.8
Hispanic	14.9
Other	5.0
Married	32.6
Live with child under age 18	9.8
Education, in years	
<12	24.5
12	26.7
>12	48.7
Years in neighborhood	
<10	11.3
10–19	16.8
20–29	12.6
30–39	19.2
40+	40.1

2.2.1. Collective Efficacy—Original Scale Items. The original CE scale, composed of eight items, first appeared in the Project on Human Development in Chicago Neighborhoods [65]. In the NOAH survey, the items were administered alongside the new CE items. The following three items were in the first block: this is a close knit neighborhood; people around here are willing to help their neighbors; people in this neighborhood can be trusted. The next five items were in the second block: your neighbors would break up a fight in front of your house in which someone was being threatened or beaten; your neighbors would do something about it if a group of neighborhood children were skipping school and hanging out on a street corner; your neighbors would do something about it if some children were spray-painting graffiti on a local building; neighborhood residents would organize to try to do something to keep the fire station open if because of budget cuts the fire station closest to your home was going to be closed down by the city; people in your neighborhood would scold a child who was showing disrespect to an adult.

2.2.2. Collective Efficacy—New Scale Items. The new CE scale, composed of eight items, was created by two of the authors. The age integration facet of social cohesion was measured with three items in the first block: people in your neighborhood treat older people in this neighborhood with respect; younger adults and children generally know who the older people in the neighborhood are; older people in

this neighborhood socialize with younger adults as well as people their own age. The answer options for each of these were strongly agree, somewhat agree, somewhat disagree, and strongly disagree. The active caretaking facet of social cohesion was measured with two items, one in each block: your neighbors would shop for groceries for you, if you were sick; people in your neighborhood would check on older or more vulnerable residents if there was a heat wave. The answer options for the first item were the same as those for the age integration items. The answer options for the second item were very likely, somewhat likely, somewhat unlikely, and very unlikely. The maximizing accessibility facet of informal social control was measured with two items in the second block: people in your neighborhood would help to keep the sidewalks and other public spaces clear if there was a snowstorm; people in the neighborhood would help to get the problem corrected, if there was a problem in the neighborhood that affected older adults, like crumbling sidewalks or unsafe parks. The answer options for both items ranged from very likely to very unlikely. The minimizing social incivility facet of informal social control was measured with a single item in the second block: neighborhood residents would intervene if an older person in your neighborhood was being threatened by a group of teenagers. The answer options for this item again ranged from very likely to very unlikely.

2.3. Demographic and Health Measures. Sociodemographic measures included age, race/ethnicity, and marital status. An indicator for the presence of a child under the age of 18 in the household of the respondent was constructed using the list generated by a household roster. Health was measured using a self-report measure that asked: overall, how would you rate your health in the past 4 weeks: excellent, very good, good, fair, poor, or very poor? We treated self-rated health as an ordinal categorical variable, collapsing the categories poor and very poor into one, because less than 2% of the sample answered “very poor”. A measure of mobility was constructed using two measures taken from the Health and Retirement Survey (2002) and two measures adapted from the California Health and Interview Survey (CHIS). The resulting ordinal variable had the following categories: has difficulty walking across a room, has difficulty walking one block, walks less than 10 minutes or more each week, walks 10 minutes or more once or a few times each week, walks 10 minutes or more daily, walks 10 minutes or more multiple times a day. Loneliness was measured using Hughes et al. [66] three-item scale. It has a range of 0 to 3 and a mean of 1.4.

2.4. Neighborhood Process Measures. Besides CE, NOAH measured two other neighborhood processes. Neighborhood disorder was measured with a four-item scale from the PHDCN and was introduced with the sentence, “I’m going to read a list of things that are problems in some neighborhoods. For each, please tell me how much of a problem it is in your neighborhood—a big problem, somewhat of a problem, or not a problem.” The four items asked about litter, graffiti, drug use and sale, and public drinking. The scale was

reliable in this sample (Cronbach's alpha = 0.74) and had a range of 1 to 3, with a mean of 1.54. Neighborhood exchange was measured with a four-item scale from the PHDCN and was introduced with the sentence, "Now I am going to ask about some things you might do with people in your neighborhood. For each, please tell me if it happens often, sometimes, rarely or never." The four items asked about doing favors, watching over homes of absent neighbors, asking for advice, and visiting. The scale was reliable in this sample (Cronbach's alpha = 0.75) and had a range of 1 to 4, with a mean of 2.8.

2.5. Analysis. In the first section of the analysis, the properties of the new CE scale were examined. Instrument acceptability and item salience were examined by comparing response rates and differential nonresponse for each item in the original and new CE scales. Next, the new scale was examined for dimensionality using principal component analysis. Because only one factor was identified, the next step was to estimate internal consistency reliability by calculating Cronbach's alpha for the new scale. Criterion validity of the new scale was tested by calculating correlations with the original CE scale. Convergent validity of the new scale was tested by calculating the correlations of the new CE scale with other NOAH measures of neighborhood processes.

In the second section of the analysis, the construct validity of the new CE scale was tested in a two-step process. First, we examined the correlations between the new scale and the health, mobility and loneliness measures, comparing the results to those from identical analyses using the original CE scale. Second, we examined whether the new scale can predict well-being more accurately in certain demographic subgroups by comparing the fit statistics of regressions estimated in those subgroups.

3. Results

3.1. New Collective Efficacy Scale: Instrument Acceptability. We first examined percentage missing for each of the items in the original and new CE scales. The items most likely to be missing in the original CE scale were "do something about kids skipping school" (4.4%) and "scold child for showing adult disrespect" (3.7%). The items most likely to be missing in the new CE scale were "younger people know older people" (5%) and "older people socialize with younger adults" (4.6%). The percentage missing one or more item from the original CE scale was 10.9%, while the percentage missing one or more item from the new CE scale was 13.0%. No clear pattern emerged of one scale showing more missing than the other.

3.2. New Collective Efficacy Scale: Differential Nonresponse. The results of the differential nonresponse analysis are shown in Table 2. Consistent with previous research, respondents in the middle and oldest age categories were more likely than those in the youngest age category to be missing at least one item from both the original and older adult CE scales [22]. The extent of this differential nonresponse by age was

not equal between scales, however. Those in the oldest age category were more likely to be missing *five* of the eight items in the old CE scale: the trustworthy neighbors item (7.9% versus 1.4%, $P < 0.01$), the scold a disrespectful child item (9.4% versus 2.4%, $P < 0.01$), the graffiti item (7.1% versus 1.7%, $P < 0.05$), the skipping school item (9.4% versus 3.1%, $P < 0.05$), and the break up a fight item (4.7% versus 0.7%, $P < 0.05$). In comparison, those in the oldest age category were only more likely to be missing *three* of the eight items in the new CE scale: the young people know older people item (11.0% versus 3.7%, $P < 0.05$), the older people socialize with young adults item (9.4% versus 3.7%, $P < 0.05$), and the neighbors intervene to protect threatened elder item (6.3% versus 1.7%, $P < 0.05$). Those in the middle age category did not differ from those in the youngest age category in their likelihood of missing any of the items in the new scale but did differ in their likelihood of missing one item in the original scale: the scold a disrespectful child item (4.9% versus 2.4%, $P < 0.05$). Because such a small percentage of the respondents were in the oldest age category (9%), we recalculated these percentages comparing the youngest old to the two older groups combined. In this case, those in the middle and oldest age categories were more likely to be missing four of the items from the original scale, but were only more likely to be missing two of the items from the new scale. In the old scale, these items were the trustworthy neighbors item (4.2% versus 1.4%, $P < 0.01$), the fire station item (3.7% versus 1.8%), the scold a disrespectful child item (5.8% versus 2.3%, $P < 0.01$), and the do something about a child skipping school item (6.3% versus 3.1%, $P < 0.01$). In the new scale, these items were the young people know older people item (7.0% versus 3.7%, $P < 0.01$) and the older people socialize with young adults item (6.0% versus 3.7%, $P < 0.05$).

3.3. New Collective Efficacy Scale: Dimensionality, Reliability, Criterion and Convergent Validity. The results from the principal component analysis suggested that the eight items in the new CE scale represented a single latent factor, since only one component had an eigenvalue greater than one. The internal consistency reliability of the scale, as measured by Cronbach's alpha, was 0.81. It was slightly higher for those over 77 and men (0.82 for both groups) and slightly lower for those 65–69 and women (0.79 and 0.80, resp.). The internal consistency reliability of the theoretically defined subscales was 0.65 (informal social control) and 0.72 (social cohesion).

To examine the criterion validity of the new scale, we calculated its correlation with the old CE scale. The correlation of the scales with each other was 0.81, the correlation of the theoretically defined old and new social cohesion subscales was 0.68, and the correlation of the theoretically defined old and new informal social control subscales was 0.72.

We next tested for convergent and divergent validity by examining the association of the new CE scale with the two other NOAH measures of neighborhood quality, neighborhood disorder and neighborhood exchange (Table 3). Neighborhood exchange was more highly correlated with the new CE scale than it was with the original scale,

TABLE 2: Percent missing each collective efficacy scale item, by age group.

	Young old 65–74 ^a <i>N</i> = 60% of the sample	Middle old 75–84 ^b <i>N</i> = 31% of the sample	Oldest old 85–95 ^b <i>N</i> = 9% of the sample
<i>Original collective efficacy scale items</i>			
Close knit neighborhood	0.9	0.1	0.3
Trustworthy neighbors	1.4**	3.2+	7.9**
Neighbors help	1.3	1.3	2.4
Fire station	1.8*	3.4+	4.7
Scold a disrespectful child	2.4**	4.9*	9.4**
Do something about children spraying graffiti	1.7	1.9	7.1*
Do something about children skipping school	3.1**	5.5+	9.4*
Break up a fight	0.7+	1.3	4.7*
Missing one or more item from the original CE scale	8.3***	13.6**	19.5**
<i>New collective efficacy scale items</i>			
Respect for old people	1.0	1.2	2.4
Groceries when sick	2.0	2.1	2.4
Young people know older people	3.7**	5.9+	11.0*
Older people socialize with young adults	3.7*	5.1	9.4*
Neighbors intervene to protect threatened elder	1.7	1.1	6.3*
Neighbors help fix issue affecting older adults	1.5	1.7	5.5+
Neighbors check on elders during heat wave	2.2	2.1	3.1
Neighbors shovel snow	1.7	2.5	0.8
Missing one or more item from the new CE scale	10.9***	14.4+	21.9**

^a% missing differs from % missing among middle/oldest old, ** $P < 0.01$ * $P < 0.05$ + $P < 0.1$.

^b% missing differs from % missing among young old, ** $P < 0.01$ * $P < 0.05$ + $P < 0.1$.

while neighborhood disorder was more highly (negatively) correlated with the original CE scale than the new CE scale. Also, disorder was more highly (negatively) correlated with the new theoretically defined CE subscale of informal control than with the new theoretically defined CE subscale of social cohesion, while the reverse was true for exchange.

3.4. New Collective Efficacy Scale: Construct Validity. In the second part of the analysis, we examined the construct validity of the new scale by comparing its correlation with various health measures with similar correlations between the original scale and those measures. The correlations between the original and the new CE scales and the self-rated health, mobility, and loneliness measures are shown in Table 4. The correlation between self-rated health and CE, whether measured with the original or the new scale, was -0.17 ($P < 0.0001$). The correlation between mobility and CE, whether measured with the original or the new scale, was 0.07 ($P < 0.05$). The correlations between loneliness and the original and new CE scales differed. The correlation with the original scale was -0.16 ($P < 0.0001$) while the correlation with the new scale was -0.20 ($P < 0.0001$).

Lastly, we regressed each of these three measures on the two CE measures one at a time and compared the fit statistics. The fit of the models, as measured by the *r*-squared statistic, was not better for one scale than for the other (not shown). We also compared the fit statistics of

these models estimated for the male and female subsamples, the married and unmarried subsamples, each of the age subgroups, and the sub-samples with and without children in their households (not shown). There were no differences in fit.

4. Discussion

The aim of this paper was to describe the development and examine the properties of a new theory-based measure of CE that incorporates the perspectives of older residents. One motivation for creating a new scale customized for a particular subpopulation is that the increased instrument acceptability and salience of the customized items may increase the response rate for the scale items. The results from our examination of the percentage missing the individual items, as well as percentage missing one or more items from the old versus the new CE scales, did not show such effects. Neither at the individual item level, nor at the scale level, did it appear that one scale is less or more likely to have missing values.

However, another motivation for creating a new scale customized for a particular subpopulation is that the increased salience of the customized items may decrease or eliminate differential nonresponse by the variables that define the subpopulation. The results from our analysis suggest such an effect in our new CE scale. The likelihood

TABLE 3: Correlations of collective efficacy scales and subscales with other neighborhood scales.

	Original CE scale	New CE scale	New CE scale—social cohesion subscale	New CE scale—informal social control subscale
Disorder	−0.39	−0.33	−0.28	−0.33
Exchange	0.43	0.53	0.52	0.41

All correlations are significant at $P < 0.0001$, except that between disorder and exchange, which is significant at $P < 0.01$.

TABLE 4: Correlations of collective efficacy scales with health and well-being.

	Original CE scale	New CE scale
Self-reported health	−0.17***	−0.17***
Mobility	0.07*	0.07*
Loneliness	−0.16***	−0.20***

*** $P < 0.001$ ** $P < 0.01$ * $P < 0.05$ + $P < 0.1$.

of missing was greater among the oldest old than the rest of the sample for five of the eight items in the original scale, but only three of the eight items in the new scale. The new scale is therefore better suited for use in older populations, because nonresponse will be less likely to be a function of age. This pattern was also in line with our hypothesis that items related to children would be less relevant and therefore harder to answer for older adults. Of the items with differential nonresponse, three of the five from the original scale and one of the three from the new older adult scale concerned young people.

The results of our dimensionality and reliability analysis suggest that the scale measures one factor, with good reliability. It has reasonable criterion validity, in that it was closely correlated with the original CE scale and the other two neighborhood scales, neighborhood exchange and disorder. It was perhaps to be expected that neighborhood exchange would be more highly correlated with the new CE scale than with the original scale, while neighborhood disorder would be more highly (negatively) correlated with the original CE scale than with the new CE scale, since the original CE scale has an equal number of social cohesion and informal social control items, while the new CE scale has 5 social cohesion items but only 3 informal social control items. This difference in the number of items measuring each part of CE may also explain why disorder was more highly (negatively) correlated with the new theoretically defined CE subscale of informal control than with the new theoretically defined CE subscale of social cohesion, while the reverse was true for exchange.

The results of the construct validity analysis suggest that the new CE scale predicts health and mobility just as well as does the original CE scale and may predict loneliness slightly better—an important finding given recent literature on the prevalence and salience of loneliness among older adults.

4.1. Limitations. The primary limitation of this study is its geographic specificity. Because it is limited to a single city, replication studies will need to examine the measure's psychometric properties in rural and suburban contexts,

as well as in other urban areas. The other limitations of this study relate to its survey modality. Phone surveys are subject to sampling and response bias, the first exacerbated by increased use of call screening technology and the rapid growth of telephone marketing [64, 67]. However, the risk of social desirability bias inherent in the telephone survey administration modality should be relatively minor given the non-personal and therefore non-sensitive nature of most of the questions asked [68, 69]. Also, sampling or response bias due to hearing impairment is likely to be less significant than such bias due to vision and fine motor impairment in studies using self-administered questionnaires [22, 70].

5. Conclusions

The importance of neighborhood context, and in particular its potential ability to modify adverse health event risk, prevalence, and severity is being increasingly recognized. For example, the original measure of CE has just recently been added to the PhenX toolkit, a set of consensus measures intended to standardize genetic and epidemiological research (<http://www.phenxtoolkit.org/>-February 4 2011, Version 4.2). While the benefits to using standard measures include comparability across studies and the potential to easily combine results in meta-analyses, there are also benefits to using measures customized to particular populations. The new measure of CE presented in this study has reliability and validity equivalent to that of the existing measure but benefits from a stronger gerontology-related theoretical grounding and reduced likelihood of age-related differential nonresponse.

The two measures exhibited both high correlation and comparable effects on the health outcomes considered. These findings raise the larger question of the extent to which measures of distinct forms of CE are capturing an underlying latent neighborhood capacity.

CE theory underscores the goal-directed nature of mobilization capacity, suggesting that a given neighborhood may have differing levels of CE depending upon the specific challenge under consideration. In this view, communities with high levels of CE with respect to the social control of public space may or may not share a comparable willingness to maintain and promote the health and well-being of local older adults.

Yet, in practice, evidence suggests that high levels of CE across multiple objectives are likely to cluster together in the same communities. This may be due to the shared origins of distinct forms of CE in the structural (e.g., economic advantage, residential stability) and social (e.g., informal

network density, voluntary organization participation) conditions of urban neighborhoods. Cohesive neighborhoods with high levels of mutual trust and solidarity may provide the conditions under which generalized prosocial norms emerge, benefiting a broad base of residential constituencies.

Although the current analysis offers evidence consistent with the notion of a generalized collective capacity, we do not view these results as grounds upon which we reject the hypothesis that CE exhibits distinct dimensions. First, CE with respect to the social control of public space may have indirect benefits for older adults. Fear and the associated withdrawal from neighborhood environments may have important health implications for older adults and may be strongly related to local norms regarding the social control of children (a significant component of the original CE scale). Thus it may be the case that the original CE operates, in part, indirectly to produce comparable associations with the health outcomes considered. Second, research on the dynamics of neighborhood collective capacities is incipient. Analyses of the association and impact of CE measures focused on other shared goals (e.g., expectations regarding influence of local institutions) may reveal different patterns, warranting more extensive research.

In the case of older adult's perceptions of their communities' association with the factors that predict whether and how older adults age in place, the strength and mechanisms are still not fully understood. For example, it may be that even before health deteriorates, specific expectations that neighbors will provide help when needed and will take steps to maintain the safety of the common areas are the particular perceptions that predict intentions to stay. Similarly, it may be that when health and functionality deteriorate, the specific perception that neighbors are assuming the caretaking role usually shouldered by family may be the particular perception that forestalls a move. This new measure of CE can be used to test these hypothesized pathways, as well as the others discussed in the introduction (Section 1), that may link CE to neighborhood satisfaction, health, and the other factors that predict intention to move and actual migration.

Author's Contribution

C. R. Browning and K. A. Cagney planned the study and designed the instrument. A. M. Galinsky performed the statistical analysis and wrote the paper. K. A. Cagney supervised the data analysis. K. A. Cagney and C. R. Browning contributed to the final draft.

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Research Article

Older People and Social Connectedness: How Place and Activities Keep People Engaged

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To understand how older adults perceive and navigate their neighborhoods, we examined the implications of activity in their neighborhoods for their health. We interviewed 38 adults (ages 62–85) who lived in San Francisco or Oakland, California. Seven key themes emerged: (1) people express a wide range of expectations for neighborliness, from “we do not bother each other” to “we have keys to each other’s houses”, (2) social distance between “other” people impede a sense of connection, (3) ethnic differences in living arrangements affect activities and activity locations, (4) people try to stay busy, (5) people able to leave their homes do many activities outside their immediate residential neighborhoods, (6) access to a car is a necessity for most, and (7) it is unusual to plan for the future when mobility might become limited. Multiple locations influence older adults’ health, including residential neighborhoods. Older adults value mobility, active lives, and social connections.

1. Introduction

The phenomenon known as “aging in place” refers to the people wanting to stay in their residence as they age [1–3]; indeed, in the US only, about 5% of people age 55 and over move each year, and half of those who do move stay in the same county [4]. Therefore, understanding the dynamic of older adults in their residential neighborhoods is important for social policy and public health programs in an aging US. As people age and their physical mobility decreases, it is assumed that their geographic world shrinks [5]. While it is relatively unclear at what ages, what levels of functional ability, or in what ways or why older adults pare down the territory in which they act, the residential neighborhood is assumed to be at the center of range. Here, neighborhood refers to individuals’ perceptions of their residential environment. This could be a historically recognized area with a name (e.g., Chinatown) or an area that is bounded by certain

streets generally accepted by those who live within it to be a neighborhood. In this paper, we examine the perceptions and uses older people make of their neighborhood and the implications for health.

A review of the quantitative literature (1997–2007) describing how neighborhoods might be associated with health for older adults identified some key limitations: (1) primarily cross-sectional studies, (2) not taking into consideration specific characteristics of older people (e.g., functional capacity and household composition), and (3) few studies which featured ethnic minority study samples [6]. Most of the quantitative literature focuses on a particular segment of the older population and describes the negative effects of living in areas with higher proportions of low-income people, highlighting crime, isolation, and psychological distress [7]. As a result, there remains a gap in the literature about what resources neighborhoods might provide to a more socioeconomically and ethnically diverse population of older adults, barriers to

accessing those resources, key features or qualities of neighborhoods that support or maintain older adult health, and whether these qualities differ by ethnicity of the older adult.

Qualitative research has examined the meanings of place for older adults and how they cope with loss (e.g., changes in the social interactions, their ability to engage with place as their capacity declines) as they age [8]. While the literature still lacks studies of ethnic minorities [9], because of its approach, qualitative methods can be more expansive than quantitative literature. Qualitative researchers conceptualize space with a focus on social relations, the power dynamics of those relations, how space is produced and reproduced, and how space contributes to identity formation [10, 11].

We sought to address the gaps in the quantitative literature by embarking on a qualitative interview study with the ultimate objective to translate these qualitative findings into survey methodology to do larger-scale studies. Two conceptual frameworks guided our investigation: social and physical insidedness [12] and environmental press [13]. We describe these briefly here. The geographer, Rowles, developed concepts of connectedness to neighborhoods and other places, specifically for older people. Rowles' term for these concepts was "place attachment." Place attachment is created through peoples' senses of places' social and physical insidedness. Social insidedness comes from everyday social exchanges over long periods of time resulting in an integration into the social fabric and an overarching identification with a locale. Physical insidedness comes from familiarity and routine within specific settings [12]. Places are redefined in the course of engaging with them. The relative importance of any attribute shifts with varied activities and memories [14]. The concept of place attachment has expanded to include cognitive and emotional bonding as well as behavioral, physical, and social connection to a community [15].

Environmental press is one of the earliest and most comprehensive ecological models of aging [13] and suggests how neighborhood environment influences health. Lawton argued that individuals behave within their environments ("person-environment fit") and respond to environmental demands ("press") depending on their abilities to cope with those demands. As people age, they experience physical and social losses, such as losses in vision, mobility, cognitive capacity, and in social support provided by kin and friends. These losses affect their interactions with their environments. Accessing resources is a means of coping. This involves a person's ability to perceive the demands that are present, interpret them as manageable, and act appropriately in response to the demand by strategically deploying the assets they command. Environmental press can be positive, negative, or neutral [13, 16–20].

More recent developments in environmental gerontology have emerged and expanded the place attachment and environmental frameworks, explicitly contributing concepts of behavior, agency, and emphasizing that these are dynamic processes [21]. The Wahl and Oswald Conceptual Framework on P-E Relationships in Later Life highlights autonomy, identity, and well-being, proposing two parallel pathways: (1) experiences (e.g., familiar routines and relationships with neighbors) leading to belonging (e.g., place attachment)

and (2) behavior (e.g., moving to change conditions as an adaptation to aging) leading to agency (e.g., altered person-environment fit). Belonging and agency both contribute to well-being. As people age, their level of agency to cope with environmental press may shift. If they are or become over time more physically frail, they may be more confined and vulnerable to negative characteristics (e.g., fewer stores, poor public transit, and lack of friends) [22]. Accompanying the changing dynamic where environment can bring more presses on the individual, one's affective connection to neighborhood may change (e.g., friends move away and feelings of connection or belonging weaken). So, if a person lives in a neighborhood for two or three decades, place attachment may increase over time and then decline with deteriorating cognitive and physical function.

The epidemiologic literature investigating how neighborhoods affect health could benefit from stronger conceptual underpinnings [23, 24]. In this literature, health is often studied in the negative, such as risk for morbidity or mortality. As such, a conceptual framework that highlights the environmental characteristics that provoke adaptation is consistent with that literature that emphasizes negative effects of poor areas such as high crime and inadequate services. The concept of belonging highlights social exchanges, routines, and attachment that develop within settings over time. Investigating belonging promotes understanding positive aspects of health, as in well-being and quality of life. Wahl and Oswald's conceptual framework (2010) highlights the intersections of the individual's behaviors within an environment together with their social experience (e.g., connections or attachment). This perspective can capture older adults' activity and how it relates to their environment, as well as identify positive environmental factors that enable older adults to use their neighborhoods. This conceptual background guided this project, as it collected qualitative data from a multiethnic sample to identify the types of resources that people use in their residential settings to maintain or improve their overall well-being.

2. Materials and Methods

2.1. Data Collection. Face-to-face interviews took place in participants' homes or a location of the participant's choosing. Interviews were conducted in English or Spanish, lasted between 30 and 180 minutes, were digitally recorded, and transcribed verbatim. After the interview, we asked the respondents to answer a brief demographic survey that included a question on self-rated health. Participants received a \$25 gift card as a "thank you." Study procedures were approved by the University of California, San Francisco (UCSF) Institutional Review Board.

To create an interview guide, we reviewed research literature that documented associations between neighborhood environment and health in older adults. We created a list of overarching topics on the basis of reported associations in the research, the two conceptual frameworks (place attachment and environmental press), and the gaps we located (e.g., not taking into consideration specific characteristics of older

adults and defining neighborhood as census or administrative boundaries). Examples of these topics are name of the neighborhood, time in neighborhood, positive or negative characteristics of neighborhood, activities undertaken in the neighborhood, changes in the neighborhood over time, typical activities in a week, and other activities. Within each overarching topic, we generated a set of specific questions to elicit people's accounts of their lived experiences, typical activities (e.g., exercise, food shopping and volunteer activities), the person-environment dynamic, how their activities might contribute to place attachment, and whether the environment created stress on the person while engaging in typical activities (e.g., if food shopping was difficult because stores were far away).

In order to allow participants to describe their experiences in their own words, questions were open-ended with probes as necessary. New questions were added on the basis of the analysis of earlier interviews. The new interview questions were then applied to subsequent interviews. For example, several participants in early interviews were very active and going to a variety of destinations on a regular basis either by driving or through adept use of public transit. In subsequent interviews, we asked about typical activities and how they got to the locations, rather than focus more narrowly on activities in the residential neighborhood.

2.2. Sampling. We recruited a purposive sample of older adults from diverse ethnic groups with a range of economic circumstances, aiming for a total of 40 participants. We recruited participants through the organizational contacts of the University of California San Francisco's Center for Aging in Diverse Communities and through professional and personal contacts of one of the authors (IHY).

Eligibility criteria included (a) aged 65 or older, (b) self-identified as White, African American or Black, Asian American, or Latino/Hispanic, (c) lived in Oakland or San Francisco, (d) lived in the same residential neighborhood for at least one year at the time of the interview, and (e) spoke either English or Spanish. Recognizing the population trends discussed above, we wanted to include participants from four ethnic groups in our interview sample, those that are strongly represented in the San Francisco Bay Area. We aimed to split the sample of 40 as evenly as possible across the four ethnic groups; moreover, recognizing that in all included groups women have a longer life expectancy than men, we aimed to interview six women and four men in each of the four ethnic groups.

Excluded were people who lived in predominantly low-income neighborhoods. Excluded neighborhoods were determined on the basis of the research team's prior experience in these areas, Chambers of Commerce data, and representations in the local media. There were two reasons for this exclusion criterion. First, was the necessity to keep the amount of variation among study participants to a manageable level given the desire to target a widely diverse group, on the basis of age, sex, and ethnicity. Second, the decision was made to concentrate the sample selection in

order to maximize the chances of exploring positive features of neighborhoods.

2.3. Analysis. Two of the authors analyzed transcripts by systematically coding text independently, guided by the interview topics as well as themes that emerged from the data [25]. Analysis took place in several stages. All transcripts were coded by the lead author and another coauthor. Transcripts were read separately and assigned codes that related to the topics and questions in the interview guide as well as other codes that they saw emerging from the data. An initial set of codes was developed. On the basis of this initial coding, a preliminary organization of the codes was constructed, loosely grouped together into larger categories or thematic domains. Subsequent transcripts were coded provoking refinement of codes and thematic domains. Coders met to discuss each transcript and the codes. Any differences of view for any of the coding for transcripts were discussed and resolved until consensus was reached. Discussions during the joint coding meetings also identified new and emergent topics and themes. The coders wrote analytic memos to describe the implications and details of these codes and the larger categories that helped organize the codes [25–27]. All codes were assigned to text blocks using QSR NVivo version 2.0 (QSR International 2006). All authors discussed and concurred with the final list of codes that were applied, the subsequent findings and interpretations of data, and linkages to the conceptual framework.

3. Results

Our final sample, diverse in terms of ethnicity and sex, comprised 38 persons ages 62 to 85 (see Table 1). When age data were checked on completion of the interviews, two people were found to be under the age of 65. Their data is included in this report because their health and activity status were very similar to that of participants over 65 years old. They lived in a variety of neighborhoods, ranging from the suburban hills in Oakland to Oakland's Chinatown and, in San Francisco, the well-to-do Pacific Heights area, the Castro (known for its gay community), and the Richmond district (known for Russian and Chinese immigrant communities).

On the basis of the analytic process described above, we identified seven key themes that fit within the Wahl and Oswald person-environment processes and place attachment framework. For experience or place attachment (belonging), there was a cluster of three themes highlighting social relations and living arrangements: (1) people express a wide range of expectations for neighborliness, from "we don't bother each other" to "we have keys to each other's houses", (2) perceptions of "social distance" between older people and "other" people (e.g., different ages or race/ethnicities) impede a sense of connection in neighborhoods, and (3) ethnic differences in living arrangements affect activities and activity locations—living with extended family, taking care of grandchildren being more common for Latinas. A second cluster of themes highlighted how behaviors might contribute to agency: (4) people try to stay busy, (5) people

TABLE 1: Descriptive information of respondents ($n = 38$).

Demographic characteristics	Overall n (%)
Age	Mean = 74 (range: 62–85)
Sex	
Men	14 (37%)
Women	24 (63%)
Race/ethnicity	
White	9 (24%)
African American	9 (24%)
Latino	10 (26%)
Asian	10 (26%)
City	
San Francisco	20 (52%)
Oakland	18 (48%)
Housing tenure—own	25 (66%)
Educational attainment	
Did not graduate from high school	6 (16%)
High school graduate	4 (11%)
Some college	10 (26%)
College degree	8 (21%)
Graduate degree	6 (16%)
Missing	4 (11%)
Living arrangements	
Lives alone	18 (47%)
Lives with spouse or significant other	14 (37%)
Lives with adult child	6 (16%)
Car ownership—yes	21 (55%)
Years living in neighborhood	
<10	10 (26%)
11–20	7 (18%)
21–40	13 (34%)
41+	7 (18%)
Self-rated health	
Excellent	4 (11%)
Very good	15 (39%)
Good	9 (24%)
Fair	5 (13%)
Poor	2 (5%)
Missing	3 (8%)

able to leave their homes do many activities outside their immediate residential neighborhoods, and (6) access to a car is a necessity for most people. A final theme emerged that indicated that many participants (those who were quite socially and physically active) did not anticipate transitioning into another phase of life should their activity levels decline and their relationship with their home and neighborhood environments shift: (7) it is unusual to plan for the future when mobility might become limited.

People Express a Range of Expectations for Neighborliness, from “We Don’t Bother Each Other” to “We Have Keys to Each

Other’s Houses.” Participants described a range of experiences with their neighbors, from detachment to friendships. Having detached or limited social relations with neighbors was common. In general, they expressed satisfaction with the way things were. At times, people noted that over several years, the turnover in neighbors had created a situation where they were not familiar with their neighbors. In these instances, they also pointed out that the newer neighbors were working age and busy during the day. The differing schedules between the older adults and the working adults meant lower likelihood of running into each other coming and going. One woman (82, Caucasian) did not know many of her neighbors, saying:

I don’t know anybody who lives up here. We did know somebody who lived up here, but they moved away, so I guess we don’t know anybody else. I know [name], who lives right behind us. . . . The other people I just wouldn’t recognize if I bumped into them on a street.

An 83-year-old, African American woman had a conflict with her neighbors regarding parked cars. The neighbors eventually stopped parking their cars in a way that blocked other people from walking on the sidewalk and then the relationship stabilized: “Yeah, and so I enjoy them, because it’s like I said, they don’t bother me and I don’t bother them. . . .” From this woman’s perspective, a good relationship with neighbors was a relatively distant one, defined by not being a bother to one another.

In a couple of instances, people seemed to indicate that this detachment was not completely consensual. A 62-year-old African American woman who lived in a subsidized senior housing apartment building talked about relations with some of her neighbors in a similar fashion:

Participant: *Another lady down the hall, she passed away, she was very nice lady. . . . but some of these Black people here, they look at you like you’re crazy or somethin’. They don’t bother with you.*

Interviewer: *Why do you suppose that is?*

Participant: *They don’t want to get involved with you.*

Some participants desired detached relations, because they preferred not knowing so much about their neighbors or being fodder for neighborhood gossip. One woman (69, African American) avoided extended conversations with her neighbor across the street so that he would not talk about her to others or attribute comments to her. In another instance, a participant was resigned not to know her neighbors well. An Asian woman (age 74), when asked about changes in the neighborhood, responded that she did not know of many: “Not really, but maybe some.” She added, “You know, here in America you don’t, not too much socializing in this neighborhood,” attributing her lack of knowledge of what was happening in her neighborhood to the lack of socializing within it.

Participants also described relationships with neighbors at the other end of the spectrum where they looked out for each other's homes, had keys to each others' houses, and called regularly to check on each other. One man (78, African American) talked about keeping an eye out on a neighbor's home when she leaves for a few days:

Well, like the lady across the street, she's a widow, she's about eighty-three. Whenever she goes to see one of her daughters she'd let me know, "I'm going to be gone three days, four days." I watch the house to see if anybody's coming around or what have you.

This participant indicated that he watched her house even when she was not out of town and made a point to talk to her at least once a week to make sure she was okay. Another participant (84, Caucasian woman) explained that a group of her neighbors have each others' house keys:

Interviewer: When any of your neighbors go away for trips or anything, do they ever ask you to look in on their place?

Participant: Well, yeah. We do that for each other. The corner house, myself and the other house, we all have keys to each others' homes. They have my key, I have their keys. Which makes it nice. Helps.

African American participants were more likely to mention keeping to themselves or not bothering or being bothered by their neighbors than did other participants. One African American woman (age 69) mentioned that she preferred that there were no sidewalks where she lived, because it deterred people from walking around her neighborhood. Latino participants were more likely to highlight social ties to people they knew through church, rather than those in the neighborhood.

"Social Distances" with People from "Other Groups". Twenty of the 38 participants had lived in their neighborhoods for over twenty years. These people often observed that there had been a lot of change in the composition of the neighborhood population and that they used to know more of their neighbors. A common experience was that the participant would recall that when their children were young, they knew neighbors who also had school-aged children. Over time, households would relocate as children moved out. The newer neighbors might be working aged, away during the day, busy with their own young children, and less available for intermittent neighborhood socializing. Sometimes, the lack of familiarity caused uncertainty or insecurity. People's discomfort was frequently a result of perceived social distance from the neighbors, being far apart in age or of a different ethnicity. A man (70, Latino) commented on young people hanging around in the neighborhood, giving him a feeling of insecurity:

In the outskirts of our neighborhood there's been more kind of young kids congregating on corners. On the business district there's more young Black

and Latino kids, maybe sometimes a White kid, too, but Black and Latino kids, kind of acting rowdy, loud.

Later, in response to a question of whether there was anything he did not like about his neighborhood, he added:

What I don't like is the sense that it's become a little more dangerous, you know, in terms of reading about assaults, and seeing kids acting out, you know, on the street. You know, fifteen year olds, acting crazy.

An older woman (84, Caucasian) who lived near a high school mentioned staying clear of the shopping area near her home when it was lunchtime. She commented:

We used to have some kids walking around and not going to school and stuff like that. But I think that goes on all over. But the only time you're really kind of bothered with it is if you go up here at lunchtime when they're all out having lunch. But you learn to stay home and avoid it so, that's about it.

Groups of young people were seen as a threat or a nuisance. There was a sense that older adults and young people belonged to separate groups while occupying the same space. People mentioned a sense of vulnerability in part due to being older with less capacity to defend oneself.

Another sort of social distance described by some was with regard to relations with people from ethnic groups different from the participant's. Latinos and African Americans mentioned tensions with Asians. A woman (62, African American) who lived in a subsidized senior housing complex mentioned that her Chinese neighbors greeted her, which she found surprising:

"Cause you know Chinese people don't... Some of them don't talk to Black people. And that was unusual for them when I was walkin' the hall she spoke to me and talked to me and asked me how I was doin'". And I was just surprised that she would talk to me.

Another woman (85, Latina) described her Chinese neighbors as not particularly friendly:

The Europeans and the Latinos are more friendly; the Chinese are ... they're not so. Well, there's one nearby to me. The only thing [she/he] says is "hello"; that's all. [She/he] doesn't come by to talk, just a hello, that's all. [Translated from Spanish]

Language may have been a factor in this dynamic around social distance. Another Latina (age 65) was concerned that storeowners in her neighborhood were taking advantage of the residents by overcharging their merchandise:

The only problem we have with the stores, is that almost all are run by Arabs. They are, how can

I say this, abusive, because they have checkout machines. The items have very small labels and the prices are always faded so it's not possible to see how much something costs. After you pay, they give you a receipt, but there's no ink, so you can't see what the price was. This is a problem for us.
[Translated from Spanish]

Asian respondents were less forthcoming about the topic of social distance though they commented about ethnic composition of their neighborhoods. An 80-year-old Asian man described that the proportions of Chinese neighbors changed over the 50 years he lived in the neighborhood. During some periods, there were more and during other periods, there were less. He mentioned this fluctuation two or three times during the interview. When asked what this fluctuation meant for his experience living in the neighborhood, he would not or could not say. A 74-year-old Asian man said it made no difference to him if his neighbors were Asian or not. Yet, he was clear that some of his closer neighbors were Chinese, while he himself was Filipino. He did say that he liked to go places to engage with Filipinos, "I will always try to go to the place where there are so many Filipinos. To me, it's enough. But when I see Filipinos, I talk to them."

Ethnic Differences in Living Arrangements Affect Activities and Activity Locations. Latina participants tended to live with other family members, in particular adult children, more than did the White, African American, or Asian participants. Four of the Latinas lived with adult children. In two of these instances, their primary activity was to look after grandchildren during the work week. In contrast, one White woman (age 71) lived with her adult daughter. However, it was not until the end of the interview, when asked whether neighbors looked after her home when she went out of town that she mentioned her daughter lived with her. The woman did very little with her daughter regularly, including sharing meals. One African American man (age 66) lived with two of his grandsons who would drive him to places, because he had chronic health problems and some difficulty walking. An Asian couple (both aged 74-years) had retired from work in the Philippines and were living with an adult son. Apart from these four people, all the other African American, White, and Asian participants lived alone ($n = 14$) or with spouses ($n = 12$). Similar to the Latina women, one of the Asian women (age 81) had been living with one of her sons looking after her grandchildren (e.g., taking them to school in the morning, picking them up in the afternoon, and cooking dinner for the family). As the grandchildren grew up and became involved in more activities, she then moved into an apartment in a nearby city that had been purchased for her by her children.

Living arrangements somewhat affected use of services, in combination with an individual's gender and type of neighborhood (i.e., whether there were retail services close by and/or easy access to public transport). Living in close proximity to family was important for all participants. Those who had children living close by could easily get assistance

when necessary. For example, an 85-year-old Latina woman was an avid gardener; her son would help her carry large bags of soil or mulch. People who lived alone did all their own food shopping, with the exception of one person who had significant mobility issues. If people lived in a suburban area with no retail close by, they would drive, often selecting the destination on the basis of prices or if they had other errands to do on the way. If people lived with a spouse, usually the woman did more of the food shopping. For one couple who lived close to shopping, the man did all the shopping because the woman had difficulty walking. They had a fixed income. He used the shopping list as his reason for walking in the morning to look at price differences at the various stores close to their home. A Latina woman (age 66) who lived with her daughter and the daughter's family might accompany her daughter to the store; however, most of her activity day during the week was at the senior center near her daughter's work and her granddaughter's school.

People Try to Stay Busy. Many of the participants were very active with social activities, work, volunteering, classes, and leisure travel. Several people talked about being "on the go," wanting to get out every day. In some cases, people intentionally went out to keep mentally and physically active. One woman (69, African American), who was in poor health by her own assessment, commented on how she likes to be on the go:

Interviewer: *Would you say that you spend more time inside at home than out and about? Or is it half and half?*

Participant: *I would say maybe half and half because I'm a goer. Yeah, and if I feel okay, I be out.*

Another woman (68, Latina) talked about being involved in many different activities:

Well, I don't have family, I don't have anyone. I am not going to sit around. I am involved in many things with the church and other things I do during the day. I don't stay here. [Translated from Spanish]

Ten of these 38 respondents participated in regular and varied volunteer activities. These included helping drive people who attend the same church to doctor's appointments, holding premature babies in a hospital clinic, visiting patients in hospitals, and helping at a meal program for the homeless. Even people who did not drive but who were interested and had the time did volunteer activities at home. For example, an 80-year-old Asian woman knitted hats and blankets for premature babies in the hospital: "I don't have to go anywhere; I just stay home and do it. And what I do is I knit hats and doilies for the hospital, and make baby afghans." Activity levels seemed to be a result of personality (being more or less outgoing), physical functioning (ability to get out), and the desire to maintain a similar level of activity as when the person was younger

(possibly to retain a younger outlook). One woman (82, Caucasian), when talking about not knowing many of her neighbors, mentioned that she's more introverted and likes to stay at home:

My husband is just the opposite, he likes people. He thinks I should be more active than I am, but I'm not. I remember that in my family, my mother was the extrovert. She was the one who knew everybody and their business. But I just don't. I'd rather stay home and read.

A 78-year-old African American widower mentioned forcing himself to get out to socialize and do things:

Well, if you go to a senior place you're around somebody all of the time, and they have activities going on. So that's the key to me to going someplace else where they have activities going on. . . . Activities for your body and for your mind.

A 64-year-old African American man, who was in relatively frail health (with gout and arthritis), regularly took a bus to his former neighborhood in order to spend time with friends. He was living in subsidized housing for seniors, located in a thriving, vibrant neighborhood in San Francisco. His friends live in an area, known for crime and disadvantage, where there is a larger concentration of African American residents. This man may not have had place attachment in his residential neighborhood, but he did have it in another neighborhood, which he regularly visited.

Perhaps in part because people are generally busy in mainstream US culture, older adults express a value in staying busy. There did not seem to be a difference amongst respondents by gender or race/ethnicity about the level of busyness [28, 29].

People Able to Leave Their Homes Do Many Activities Outside Their Immediate Residential Neighborhoods. Half of the participants went out of their neighborhoods at least once a week for a variety of reasons. In addition to the activities listed above, weekly activities included going to the movies, participating in hobby or social groups (e.g., bowling league and hiking group), food shopping, caregiving for a friend or relative, window shopping at the mall, or visiting family. Other regularly occurring (monthly or quarterly) events included going to doctor's appointments and picking up prescriptions. The neighborhood was not a key location for the majority of these activities. The most common activity done close to home, mentioned by 13 of the participants, was walking in their neighborhoods. Half of the participants lived close to retail areas with a large array of businesses or were within easy walking distance to smaller commercial districts where there might be a café, a few stores, and a couple of restaurants.

Combined with the emphasis of striving to be busy and on the go described above, this theme highlights the sometimes extensive geographic distance covered by many older adults on a regular basis. While each person's sense of neighborhood physical boundaries differed, activities outside

perceived residential boundaries were very common. For example, an 82-year-old man went to the movies twice a week, generally travelling on foot and by bus to go to his favorite theatre about three miles away from his home. A 69-year-old woman drove about seven miles from her home in Oakland to Oakland's Chinatown, two to three times per week, to volunteer activities and buy food. A 78-year-old man travelled by bus Monday through Friday morning five miles to a senior center in the Mission District of San Francisco to visit with friends.

Two people did not leave their neighborhoods. One woman (age 63, African American) had severe arthritis and needed someone to do her grocery shopping for her. Her busyness came in the form of watching television and speaking to siblings on the telephone frequently. The other (an 84-year-old Asian woman) lived in a retail-rich area of San Francisco and did some errands in her neighborhood. When she left the neighborhood, it was for doctors appointments.

Access to a Car Is a Necessity for Most. Related to the theme above, having easy access to a car was a perceived to be a necessity. Twenty-one people either drove themselves or had access to a car when, for example, a child or grandchild would drive the person where they needed to go. A woman living in Oakland (72, Caucasian) said, "Well, we wouldn't be able to stay here without being able to drive. I suppose we could use taxis, but that would be the only alternative." A 69-year-old, African American man in Oakland said, "I would say that there are no stores. And that's one of the major difficulties of living here is that if you don't have an automobile you're up the creek."

It Is Unusual to Plan for a Future When Mobility Might Be Limited. As noted above, we spoke to many people who were socially and physically active, commonly driving outside of their neighborhoods for their activities. We asked people if they had made plans for a time when they might not be so mobile or able to get out so easily (e.g., if they could no longer drive). Five participants were living with an adult child. One couple who had retired in the US from another country, assumed that at a certain point when they were frailer, they would move back to their home country for access to affordable support services. A Latina woman, widowed, originally from Nicaragua, mentioned a similar plan. The others assumed they would continue to live with their adult child and would be able to rely on them. Three participants mentioned that if a time came when they could not get around easily, they would likely move in with an adult child living close by. Some people indicated that they would move to an institution. Others mentioned that they have thought about having a paid caregiver move in to their home. More commonly, people had not given too much thought about it:

I think I'm just going to rely on my daughters, or my granddaughter by that time. . . . I have a couple of girlfriends who live up here in the same situation I am, and, you know, we have talked about that, how maybe we can help each other

drive or something. But, no, I have to admit I have not given it a lot of serious thought. (69, African American woman)

Most of the participants adhered to the aspiration to age in place and stay in their current living situations for as long as possible. Given the high level of activity that these older adults maintained and their reliance on the car to be so active, we anticipate that it will become increasingly important to understand how to support older people and their desired activities and lifestyles as they become frailer.

4. Discussion

The US population is aging and is increasingly non-white. Current population projections for the US predict that by 2050, the proportion of non-Whites over age 65 will double (from 19% to 39% of the population of age 65 and older people), the proportion of Latinos will triple (from 6% to 18%), the proportion of African Americans will increase by one-third (from 9% to 12%), and the proportion of Asians will nearly triple (from 3% to 8%) [30]. Understanding how neighborhoods and other places affect older adults from different ethnic backgrounds could contribute to policies to address ethnic health disparities.

Through qualitative interviews, we learned about urban older adults' activities both in their residential environments and elsewhere. Participants spent time in their neighborhoods walking and had varying levels of engagement with their neighbors. For participants who were physically able to move about, other than walking or socializing, if the neighborhood did not include retail locations (as was more common in Oakland than San Francisco), then it was not the setting for regular activities. Participants drove their cars to many other destinations to volunteer, exercise, shop, and socialize.

When applied to these data, the Wahl and Oswald conceptual framework (2010) uncovers some new perspectives on the neighborhood-health dynamic for older adults. Since many of these older adult participants maintain a high level of "busyness" and travel to nonneighborhood locations for a variety of activities, this suggests that it is common to live on a geographic scale greater than the residential neighborhood and that social and material needs are fulfilled by doing activities in a broader space. This has implications for social policy addressing "aging in place," suggesting the need to provide access to spaces beyond the residential setting. The neighborhood does provide opportunities for social interactions and at times social connections, a basis for the experience-to-belonging piece of the Wahl and Oswald framework (2010). But for the most part, participants in our study largely described detached and distant relations with their neighbors and furthermore expressed satisfaction with this state of affairs. Indeed, the social distance theme reflects a trajectory from that of a form of place attachment (knowing ones neighbors well and having lots in common because children are going to the same schools) to a position of feeling a poorer fit with the neighbors, a form of environmental press, with the change in composition to

households that are different in age and/or ethnicity. At the time of the interview, for a relative few, the social ties within neighborhoods were positive characteristics, but in most other cases, the social interactions were sources of tensions or negative environmental press, using the language of Lawton's person-environment framework. Lawton's conceptualization of environment encompassed the personal environment (e.g., spouses and coworkers) and the group environment which referred to the influences of an aggregation of individuals (e.g., neighbors) [31, 32]. The age, race/ethnicity, and language composition of others in the neighborhood contributed to whether these factors were perceived to be part of the press that the environment imposed, and that limited engagement in the neighborhood or, conversely, as a resource residents could use to meet environmental demands.

We found that people prefer to stay busy and their ability to do so is heavily dependent on having access to a car. Indeed, while all but three people very much wanted to continue living where they were, their primary social and shopping activities occurred outside of their immediate neighborhoods. When asked to think about a time when they might not be able to drive or get around on their own, most people had not given serious consideration as to what they would do under those circumstances. Therefore, for those without access to a car or for those who have no relatives close by and who would likely experience constrained mobility in the future, the features and resources within the neighborhood are and would be important.

As concepts in environmental gerontology have been refined in the last twenty years, the dynamic process of aging has been more explicitly incorporated [22, 33, 34]. With our participants, chronological age did not clearly correspond to physical function or limitations. The youngest three participants, all African American, were in the poorest health. This is consistent with the trend that African Americans develop chronic conditions at younger ages than their White counterparts [35–37]. On the other hand, one of the oldest participants, also African American, had no chronic conditions, and was extremely active, visiting people in the hospital, attending community meetings, and active in her church. Chronological age is not necessarily the most optimal categorization for these participants. These complexities further corroborate the Wahl-Oswald conceptual framework (2010), especially the pathway from agency to identity. Moreover, the arrows along this pathway could potentially also be bidirectional, with the possibility that identity affects behavior, and in turn agency. For our participants, "identity" is tied to group identity, which is informed by social definitions and positions, often less tied to geography, and which motivate behaviors through which individuals seek to affirm and reinforce those identities.

Our longer-term objective in conducting these interviews is to translate the findings to conduct larger-scale survey research. The quantitative research literature on neighborhood-health associations for older adults sometimes uses age (as measured by the proportion of people age 65 and older in the census tract) or ethnic composition (quantified by measures of segregation) among the important demographic

characteristics to describe the neighborhood. Our qualitative study supports the significance and continued inclusion of these variables. Our participants confirm what past research, in particular on intentional communities for older adults or age-segregated residential facilities [38, 39], has found, namely, that older people felt more comfortable if there were other older persons living nearby. There was a sense among our participants that younger neighbors were busy with their lives, coming and going, with not much time or interest in older people or any of the other neighbors.

For ethnic composition, existing evidence and our study findings are more equivocal. Studies have reported that African Americans who live in areas with higher proportions of African Americans have poorer health compared to African Americans who live in areas with lower proportions of African Americans [40, 41]. Other studies have reported that older Latinos who lived in areas with higher proportions of Latinos have better health than Latinos who live in areas with lower proportions of Latinos [42, 43]. The participants in this study did report tensions or uncomfortable interactions with people from other countries or who spoke other languages. Feeling different than, being taken advantage of, or overlooked by racially and ethnically dissimilar neighbors appeared to constitute sources of environmental stress with negative effects on neighborhood engagement. Ethnic diversity can be experienced as dissimilarity, as not belonging, as the opposite of place attachment, when residents perceive it to stand in the way of forming social ties to neighbors. The literature also clearly shows that racial/ethnic concentration, when it is a product of segregation, marginalization, and disinvestment in particular communities, is not conducive to health. Our qualitative data support the notion that rather than neighborhood racial/ethnic composition, in and of itself, being important to health, it is a combination of a neighborhood's composition and attendant social, economic, and political resources—or a lack thereof—that are meaningful for residents' health.

Epidemiologists seek to conduct large-scale, longitudinal studies in multiple locations to produce generalizable population-based findings. The findings from this qualitative research project can be used to inform the contents of a survey for a larger-scale study. On the basis of the key themes reported here, future studies should ask questions about older adults' perceptions of their neighborhood boundaries, where else they regularly spend time, the extent to which they are influenced by the social and physical environment of other neighborhoods in which they spend a significant amount of their time, and their use and reliance on a car or public transit. Future research could extend the Wahl-Oswald framework to these other locations, sometimes referred to as activity spaces [44] and consider the possibility that older adults find and experience place attachment in these more geographically distant places as well as close to home. To date, modest associations have been reported for the neighborhood influence on health status for older adults. Investigating other activity spaces for their resources, demands, and attachments could suggest other mechanisms through which place influences health for older adults.

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Research Article

Negotiating the Joint Career: Couples Adapting to Alzheimer's and Aging in Place

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To understand the impact of memory loss on aging in place, this paper investigated dyads where one spouse had been diagnosed with memory loss. In-depth qualitative interviews were conducted with ten couples ($N = 20$). Grounded theory methods were used to collect, code, and analyze data into themes. Data revealed consensus among and between dyads that it was best to focus on living, rather than what had been or might someday be lost. Nonetheless, differences according to gender and cognitive status (e.g., diagnosed or spouse) were reported. Given population aging, identifying the impact of gender roles and social norms on the potential for aging in place with memory loss is critical. Community services and care practices must be sensitive to the ways that couples prioritized and organized their relationship prior to diagnosis in order to encourage positive patterns of care between couples, foster successful adaptation to changing needs, and support in-home arrangements as long as possible.

1. Introduction/Background

Recent policy and service initiatives have focused on helping older adults remain in their current homes for as long as possible, that is, to “age in place.” Research has shown that older adults prefer to stay in their homes [1]. In addition, movement from familiar surroundings can have deleterious effects on health, economic factors, and quality of life, especially for persons with dementia [2–4]. A recent report [5] explored anticipation of relocation from a naturally occurring retirement community (NORC) in a nonrandom sample of 324 community-dwelling older adults. The 26% of NORC residents who worried they would have to move cited physical health, finances, physical structure of the home, and social isolation as the most common reasons.

Over the past few decades, a rich literature on aging in place has flourished within environmental gerontology. The interdisciplinary field has examined the unique role of place, or the built environment, on experiences and meaning of life. Environmental factors are now recognized as having a significant impact on quality of life for seniors in general

[6–9] as well as persons with dementia in particular [10–15]. Scholars have explored the meaning of home to seniors and how this may be fostered or disrupted by changes related to aging [7]. Although the vast majority of this work focuses on institutional settings, quality of experiences in long-term care that is not nursing home care has been examined [8–10]. This is especially important for seniors living alone since the home environment and personal space are often the most significant variables facilitating their independence [8]. Home takes on a particular meaning in old age because it can compensate for reductions in functional and/or cognitive abilities [9].

The importance of physical and social environments for ensuring quality dementia care has been of growing interest to the field [12]. Research [14] suggests that built environments are shaped by unifying philosophies or goals and that “relationships between the various components of place—organizational, social, architectural, and experiential—are typically far from random,” but instead “work towards the overarching goal of the environment shaping social attitudes and patterns of behavior” [15, page 13]. This model argues

that built environments are experienced through perception, cognition, action, affect, and meaning. “For people with dementia,” others add, “memories of the places in their lives and the events, emotions, and experiences associated with those places may help provide continuity even as cognitive and communicative abilities dwindle” [11, page 8]. Accordingly, evoking such memories can assist in “rediscovering the self” for persons with dementia.

The role that family members can play in eliciting the shared biographies (and events that predate the family member) is crucial to such self-preservation. Although this work explicitly addresses reminiscence as a tool to be used in institutional settings, many of the recommendations can be extended to the individual home environment as well. Since “place and memories of place play an important role in shaping—and sustaining—our sense of self” [11, page 22] and memories of home are part of our self-identity, family members of persons with memory difficulties can prompt pleasant past experiences. This model is in line with Kitwood’s seminal thesis that “person-centred care” involves knowing the life history of individuals with dementia [16]. In this case, compassionate others can support the narrative identity of persons struggling to remember.

This impressive body of research elucidates the critical role family members, particularly spouses, can play in helping individuals with memory loss reminisce, and thus maintain self-identity. It also highlights the unique features of aging in place after having lived somewhere for several decades as a couple. For example, persons who lived at a home prior to becoming forgetful will arguably be able to maintain more independence in a place that is familiar and involves routines than they might be if relocated. Environmental gerontologists have discussed the ability of personal experiences to attribute meaning to places in terms of “insiderness” [6]. For persons living with dementia who reside with a spouse, experiential familiarity or “physical insiderness,” patterns of interdependence or “social insiderness,” and a sense of belonging or “autobiographical insiderness” are all crucial to aging in place. Both the existence of familiar routines and reminders of significant life events and places can help provide continuity in spite of cognitive decline, thus allowing persons with dementia to potentially stay at home far longer than might be the case otherwise.

1.1. Alzheimer’s Disease. With the aging of the populace, individuals are more likely to develop chronic diseases such as Alzheimer’s (AD). Historically, research has largely overlooked the social interactions and sociocultural frameworks in which forgetfulness occurs [17, 18] despite the fact that psychosocial factors influence the quality of aging experiences. The majority of older adults have multiple chronic medical conditions that may impair everyday function leading to increasing vulnerability [19]. These conditions may affect the ability to make independent decisions, forcing older adults to rely more heavily on outside forces such as their spouses for assistance in making major decisions regarding health, lifestyle, and living arrangements. Knowledge of proximal determinants of behavior is important

because it allows identification of variables that are more readily amenable to change [20].

Alzheimer’s disease and its prodrome, mild cognitive impairment (MCI), have historically been interpreted within a biomedical framework, and the assumed impact has been presented as universally devastating for diagnosed individuals and family members alike. Cross-disciplinary research demonstrates that social perceptions of dementia are generally negative [21–23], yet subjective experiences of living with the diagnosis and providing care vary by racial/ethnic, socioeconomic, and gender status [24, 25]. While many studies have focused on the individuals’ struggle to avoid assuming the (pejorative) Alzheimer’s identity [26–29] or the courtesy stigma of having a family member with dementia [30, 31], only recently has research begun examining dementia as experienced by couples [32–37]. In addition to the trend of increasingly earlier diagnosis, this shift has likely been precipitated by the nearly 5.3 million Americans with AD being cared for within their homes, primarily by spouses [38].

Previous studies on “couplehood” suggest that the experiences of persons with AD and their spouses are heavily influenced by a medicalized explanatory framework, the reciprocity of spousal bonds, and stereotypical rhetoric of loss [35, 36]. Alzheimer’s diagnoses create an opportunity for both diagnosed individuals and their family members to either accept or reject the label. In support of previous research [26, 27], individuals often vacillate between openly embracing the label and trying to avoid being associated with its “master status,” therefore both minimizing and exploiting processes of medicalization. This simultaneous acknowledgment of and resistance to the label has been used to highlight the inappropriateness of talking about the “acceptance” or “denial” of AD [39]. Understanding the Alzheimer illness identity as pendular rather than linear is, therefore, particularly salient. Previous findings have suggested that couples work together, describe dementia as part of the normal aging process and focus on positive thinking to avoid the social stigma associated with an Alzheimer’s diagnosis [35] and to maintain both personhood and couplehood.

Debates over the relationship between illness and identity [40, 41] represent diagnosed individuals’ struggle between biomedicine and a sense of self-worth [42]. Using a symbolic interactionist and social constructionist lens [43–45], we examine how individuals diagnosed with memory loss and their spouses make sense of and manage the deeply emotional and stigmatizing experience of living with memory loss. A couple’s interpretation of AD is affected not only by a medicalized society, but by their unique social and relational contexts.

Research demonstrates that negotiations between AD and the self are dependent on spousal interactions, with support persons potentially providing extensive restorative identity work [46] to downplay (the exclusively negative) AD identity and to maintain couplehood. Using Glaser and Strauss’ seminal work on awareness context theory [47], we argue that experiences of memory loss are based on relational capacity that will be negotiated differently by a couple than an individual and impacted by factors unique to each couple.

Furthermore, during “shared awareness” both the diagnosed individual and the care partner will remain active [35]. Through investigating dyadic relationships (predominantly defined as couples but other caregiver-recipient pairs have also been utilized), studies have begun to demonstrate a sense of “we do it together” and a breaking away from the traditional pejorative framings of Alzheimer’s disease and so-called “caregiving.” An innovative body of research has reported noteworthy exceptions to this assumption by demonstrating positive and/or spiritual experiences of both living and caring for someone with Alzheimer’s [26, 28, 48–51]. Recent studies have even suggested that enhancing the dyadic relationship may help slow Alzheimer’s-related decline [52] and decrease psychosocial costs to carers [53]; thus encouraging positive adaptation to the condition and increasing the likelihood of aging in place. Indeed, even interventions aimed at improving social support and coping skills have effects on both parties, including reduced caregiver depression, improved well-being, and delayed entrance into nursing homes [54, 55]. It is now well documented that diagnosed individuals understand the social and psychological aspects of AD, including social (mis)perceptions of diminished dignity and value [56]. Accordingly, for those who are coupled, this crucial social relation can be essential to positive experiences of memory loss and continued in-home living. This is the basis for our analysis, as we found evidence in stark contrast to the traditionally negative view of “suffering” in relation to memory loss. This article will explore the role of spousal dyads on efforts to adapt to memory-related changes and to age in place.

This study compares how diagnosed individuals and those who care for them define AD and narrate their subsequent experiences and how this impacts efforts to maintain personhood, couplehood, and the desire and/or ability to remain living at home together. Based on recent findings that dementia is a “collaborative venture” and that the “us identity” of the couple is preserved in spite of the diagnosis of dementia [33], we, too, investigate couples’ joint production of meaning. We also add to the research on “couples’ shared constructions of, and responses to, the diagnosis” that reveals oscillating processes of meaning-making and adjusting to dementia [37, page 337]. Thus, we borrow from Karp [57], when we argue that spouses have a “joint career” of memory loss; a career which is socially constructed and negotiated. In so doing, our data suggest that dyads dealing with memory loss together, or “negotiating its impact” [58] and “co-constructing caring” [59], are more likely to remain positive, maintain a sense of self and couplehood, remain living at home, and evade the typically negative framework attached to the condition in America.

2. Methods

These data are a subset of a larger study, entitled ACCESS (Assessing the Cultural Characteristics of Elders and the Support Systems), exploring first- and second-hand narratives of early-stage memory loss. The purpose of the research was to examine everyday life with memory loss, including AD and MCI. The sample reported here contained only

dyad interviews and is analyzed separately from the larger cohort to permit investigation of the impact of gender and relationship to memory loss (diagnosed or support person) on the joint experiences of couples confronting AD/MCI. Positing that couples interact within marriages by constructing symbolic and shared realities, we sought to investigate how their common perceptions might be altered by memory loss. That is, how do couples make sense of and respond to memory loss and the impact it has on their relationship? If meaning is produced as a joint venture within dyads, then how might memory loss influence their shared reality?

Ethical approval for the study was obtained from the Institutional Review Board at the University of Illinois Chicago (Protocol no. 2005-0839). The present paper reports on in-person dyadic interviews conducted with coresident, married couples dealing with memory loss. All interviews took place in the couples’ home. The research was based on a nonprobability sample using convenience sampling. Grounded theory techniques were employed to collect, code, and analyze data by consolidating textual data into broad themes.

2.1. Sample. The inclusion criteria for participation were expert diagnosis with AD/MCI at a specialty memory clinic and the presence of a spouse dyad. These criteria allowed us to target the experiences of those diagnosed with memory loss and their family members. The sample included ten dyad interviews with individuals experiencing memory loss and their spouses ($N = 20$). All ten individuals diagnosed with memory loss were evaluated at a specialty memory clinic and meet criteria for either Alzheimer’s or mild cognitive impairment. Criteria included MMSE (Mini-mental state examination (MMSE; Folstein, Folstein and McHugh 1975) scores range from 0–30, with 30 being perfect.) scores between 20–30 (out of a possible 30), where lower scores signify the presence of progressive cognitive impairment. The average MMSE score for diagnosed respondents was 25 (ranging from 22 to 30). Individuals diagnosed with MCI did not meet clinical criteria for AD, but had subjective memory complaints and were greater than 1.5 standard deviations below the norm (adjusted for age and education) on the neuropsychological tests. All ten diagnosed individuals were considered in the early stages of AD ($n = 7$) or its prodromal stage MCI ($n = 3$; at the time this research was conducted, a clinical diagnosis of MCI was considered a potential precursor to Alzheimer’s. New diagnostic guidelines released jointly by the US Alzheimer’s Association and National Institute on Aging in April, 2011 redefined MCI as an official “stage” of Alzheimer’s). The average time since diagnosis was just under 3 years, but close to half had been diagnosed roughly two years prior to being interviewed.

Our dyads included 6 male patient-female spouses and 4 female patient-male spouses. Ninety percent of our couples lived in urban settings, with only one dyad residing in a rural area. The vast majority of the respondents stated their race as Caucasian, with one couple identifying as Hispanic. All dyads lived together, and one couple had young

children living in their household as well. All informants completed at least twelve years of schooling; 9 of the 10 couples having at least some college experience. The mean age of our respondents was 73 (ranging from 50 to 89 years old). The median income was \$65,000–\$99,999, with only one couple reporting an income level below \$20,000. No significant differences in demographic characteristics between the male diagnosed-female spouse and female diagnosed-male spouse dyads or the AD and MCI dyads were found. See Table 1 for the specific demographic data on the complete sample.

2.2. Qualitative Analysis. This research was informed by an inductive method of data collection, sampling, and analysis. Rather than strictly testing hypotheses or applying existing theories to data, the aim was to generate theory that is “grounded” in the data itself. As such, the product of this research is a midrange substantive theory and its generalizability lies in the concepts discovered within the sample studied rather than the larger population from which it was drawn.

The first author, and principal investigator, conducted all interviews in person using a semistructured interview guide (see Table 2). Since respondents were seen as the experts on the topic, interviews were conducted in an informal, open-ended manner to allow dyads to tell their unique stories of memory loss. Given the dearth of existing data including both perspectives simultaneously, interviews aimed to elicit the shared story of each couple rather than test specific hypotheses. The questions from the interview guide were used as probes to generate conversation without following a standardized format. The only question that was asked of every dyad was: “Can you tell me what your life together has been like since [name] was diagnosed with memory loss?”

All interviews were audio-taped, transcribed, and then analyzed using the constant comparative method and coding paradigm of grounded theory [60]. Since this method aims to consolidate information into matrices in an effort to generate overarching themes, the on-going process of taking notes, writing memos, and (re)reading data lends itself to emergent categories for simplifying and articulating data.

Detailed notes were dictated immediately following all interviews. Paid assistants transcribed each taped interview verbatim, yielding 311 pages of narrative transcript data. The PI verified transcript accuracy by reading each one upon receipt. Additional quality control measures (i.e., listening to transcripts while playing the data files) were performed on 100% of the subsample used for the present analysis.

Analysis began with “open coding” which involved identification of the dimensions and properties of the themes in the margins of textual data line by line. Next, themes were consolidated by using an explanatory matrix to identify major “core variables.” To ensure reliability of the findings, two research assistants (SS and VI) read all textual interview files, provided detailed analysis notes, and line-by-line coded each transcript. The common themes for the subset of spousal dyads will be reported here.

3. Findings

In support of previous research [32, 35], couples in our study did not dwell on their respective experiences of AD. Rather, they expressed a desire to “keep on keeping on,” which appeared to minimize the impact of a diseased identity and help avoid their being consumed by the condition. As reported elsewhere [37, 61], this led them to try to emphasize the “retained abilities” [29] of the diagnosed counterpart and their joint identity rather than focus primarily on the various losses, or symptoms, associated with memory loss. Importantly, this involved both parties knowing when they needed support.

3.1. Manageable Disability.

I consider myself to be very—you know, I’m very happy. And, you know, when I am not clear about something, I just talk to [husband] about it or figure it out myself. I mean, it takes me a little longer, perhaps, than somebody who did not have Alzheimer’s, but, you know, that’s not a problem. You’re just sometimes a little bit slower. Wouldn’t you say? [asking husband, who concurs] So, I mean, we sort of do things together (female, with AD).

We think that even now in most—if you get early diagnosis, it’s a manageable disability if you get the help, you know, a little bit of help (male, wife with AD).

I do not want to focus on [Alzheimer’s]. I do not need to. So far, we are going along fine. We are both happy and we sleep together. He tells me 5 or 10 times a day that he loves me. He gives me a kiss and hug when he goes down stairs and comes back. He thanks me for every meal. He washes all my dishes. He has for years and years. He does not do as many things around the house. But, he found an error in our statement that the bank had made that I overlooked. He’s pretty sharp at that. He watches the bank statements (female, husband with AD).

Similar views were reported by all 10 dyads in our study. Diagnosed individuals’ desire to avoid being equated with a given condition is well-established within the medical sociological literature [27, 28, 42, 62] and our findings demonstrate that the spouses of people with AD support them in this endeavor. Within relationships framed by positive experiences and a lifelong commitment [32], this shared outlook was the most common strategy to maintain “couplehood” [35, 36, 63] reported in our study.

As suggested elsewhere [32], when the reaction to changes related to memory loss are experienced within the context of those associated with aging generally, they are perhaps less traumatic and/or disruptive. Furthermore, familiar environments with positive relationships and shared constructions of meaning support both couplehood and

TABLE 1: Study demographics.

	Mr.* and Mrs. J	Mr.* and Mrs. D	Mr.* and Mrs. R	Mr.* and Mrs. F	Mr. and Mrs. M*	Mr. and Mrs. A*	Mr. and Mrs. B*	Mr. and Mrs. K*	Mr.* and Mrs. S	Mr.* and Mrs. P
<i>Age</i>										
45–55 years			XX							XX
56–64 years									XX	
65–74 years	X			XX				X		
75–84 years	X				XX	XX	XX	X		
85+ years		XX								
<i>Race/ethnicity</i>										
African American										
White, not Hispanic	X	X	X	X	X	X	X	X		X
Hispanic or Latino/a									X	
<i>Marital status</i>										
Married	X	X	X	X	X	X	X	X	X	X
<i>Living status</i>										
Coreside	X	X	X	X	X	X	X	X	X	X
<i>Residence</i>										
Rural					X					
Urban	X	X	X	X		X	X	X	X	X
<i>Education status</i>										
< High school										
High school graduate or GED									X	
Some college, technical/vocational		X	X		XX					
≥ College degree	X	X	X	XX			XX	XX		XX
<i>Annual income</i>										
< \$20,000									X	
\$20,000–\$39,999										
\$40,000–\$64,999					X		X			
\$65,000–\$99,999	X	X						X		X
> \$100,000			X	X		X				
<i>Residence</i>										
Rural					X					
Urban	X	X	X	X		X	X	X	X	X
<i>Diagnosis</i>										
AD		X			X	X		X		
EOAD			X						X	X
MCI	X			X			X			
<i>Time since diagnosis</i>										
2–3 years	X			X	X					
3–4 years		X	X				X	X	X	X
5+ years								X		

*This individual was the spouse who had been diagnosed with AD/MCI.

TABLE 2: Tentative interview guide.

(A) Subjective experience
(i) When did you first realize changes in X's memory?
(ii) Who noticed the changes first? Did you feel comfortable sharing your thoughts with the other?
(iii) Tell me about your experiences leading up to being diagnosed.
(iv) How do you define Alzheimer's disease (AD)/mild cognitive impairment (MCI)?
(v) What does AD/MCI mean to you?
(vi) What has your experience been like since the diagnosis?
(vii) What are the biggest changes that have happened in your life since the diagnosis?
(viii) How would you describe your relationship prior to diagnosis?
(ix) How, if at all, has your relationship changed since the diagnosis?
(B) Social experience
(i) How, if at all, have your interactions with others changed since diagnosis?
(ii) Tell me how you think your diagnosis affects your loved ones, if at all.
(C) Miscellaneous
(i) Are there any unexpected things that have come from your experiences with Alzheimer's? Any "silver lining" to your situation?
(ii) How do you envision the future?

aging in place. Despite consensus on the importance of continuing to live as normally as possible and the positioning of memory loss as a "manageable disability"; however, the "united front" couples presented also involved within-dyad gender differences in coping strategies and disagreement over perceptions/outlook, as reported elsewhere [64].

3.2. Support Persons Find Individual "Tricks" versus Group Support. Female support persons were more likely than their male counterparts to rely on concrete strategies such as note writing and calendar keeping in helping them deal with their spouses' memory loss:

I have to find out the different tricks myself. We have a calendar on the refrigerator and I have to put everything on the calendar. . .where I will be at, if I have to work, if I'm getting a hair cut or getting my nails done, we're going out to dinner. Whatever we are doing I put on that calendar (husband with MCI).

I've always put notes around. I've tried to get [my husband] to do it but he wouldn't do it. He wouldn't put notes around. He was fine if you gave him a note and you left him a list (husband with MCI).

Male support persons, in contrast, commonly turned towards interactive, collective resources such as support groups or churches as a form of coping with their wives' memory loss.

We have a great group at church [that provides support] for everyone dealing with this (wife with AD).

There's one thing that I wanted to talk more about with the support group—one of my neighbors right down the street here has got a similar situation, and she goes to the support group, the same place I do, but at a different time. And I just wonder if maybe we could all get together and go to the same support group, which would be a little bit better (wife with AD).

Although spousal carers report similar efforts at "managing forgetting" [65] as do diagnosed individuals themselves [66, 67] male and female support persons in our study ultimately found different strategies helpful in coping with their spouses' memory loss. While our data perhaps corroborate suggestions of a gendered dynamic to caregiving, including increased burden for wives [68], husbands more likely to normalize symptoms [69], husbands having more outside support available to them and less restrictive social activities [66, 69, 70], and problem-solving (male) versus hands-on emotional (female) coping [71], it is crucial to acknowledge the social determinants of health and cultural influences on beliefs, especially in such a small study, to avoid reductionist claims based on gender.

3.3. Support Persons Promote Autonomy versus Admitting Discontent. Although memory loss can greatly decrease someone's ability to perform certain tasks, our female support persons promoted as much autonomy as possible in their spouses, seen most clearly in the instances of driving and use of humor to minimize problems.

The time will come when we will have to talk about a driver's evaluation. But I do not think I'm going to be the one to talk about it, and that's what they wanted me to do. . .And I just—I'm no expert. I'm in no position to say "[Husband's name], you'd better have your driving evaluated" (husband with AD).

He used to forget directions. When we drove anywhere, very familiar places, he would forget how to get there. And when he got there, he would forget how to get home. If he went into a parking lot, he would not know which way to go back. Sometimes, I would just let him go and he would say, "what are we doing here?" I'd say, "I thought you were taking me out someplace new for dinner." We have continually laughed. I think is very beneficial for us (husband with MCI).

Occasionally, he'll go down stairs to pick up the mail. He'll come back up and he does not have it. "Oh you do not have the mail." "Oh, I forgot." He'll go back down and do it. Sometimes and goes backwards like this and the blood goes out of his head or something.

If there is something that could be taken as a reprimand or disappointment, like he forgot to bring the paper or he did not bring the mail, I've learned not to say anything. It's better to let it go (husband with AD).

While these data suggest that perhaps wives providing care are more concerned with maintaining reciprocity in relationships or active engagement with their husbands despite memory loss, it is equally plausible that it underscores the need to understand the "contextual nature" of husbands' narratives [72]. Likewise, these data may lend support to findings that relational aspects were more important for female than male carers [68], but they might also demonstrate the difficulty of challenging traditional gender roles for women [69] and/or caregiving wives' stronger concern with how other people perceive their husbands. Such "saving face" strategies have been reported elsewhere [66].

Unlike previous findings [35], however, our male support persons did not focus solely on meeting their wives needs or upholding their autonomy. In concert with other studies [56], our data reveal husbands who vocalized the discontent and disruption that they faced in providing care for their wives with Alzheimer's.

Well, a few times she's gone out and gotten lost, and I've gotten kind of worried about it...There's no place else that she goes [other than on walks] really. I have to let her do that. Everything else, I go with her, which is kind of a nuisance sometimes (wife with AD).

I've found it hard even to go out and cut the grass because if I'm out there an hour, she's probably out there 3 or 4 times asking me a question (wife with AD).

While the wives in this study stressed their husbands' independence and their retained capacity for making valuable contributions, the husbands providing care were more vocal about their own hardships. This focus on "other" versus "self" is a potentially important distinction in methods of caring, which demonstrates the inadequacy of supportive services that assume a uniform approach based on the perspectives of predominantly female carers.

3.4. Perceptions of AD According to Diagnosis. As reported elsewhere [64], there were also important differences between diagnosed individuals and their spouses as regards reactions to and interpretations of memory loss itself and perceptions of the future. The following quotes demonstrate this divergence in defining Alzheimer's.

It's an old disease. [It's] just the deterioration of your brain capacity (male, MCI).

[AD] isn't a disease. It's an animalistic type of thing I think because you can see it in a lot of animals as they get older. They don't act the same (male, AD).

In contrast, spouses reveal different interpretations.

It's a disease of your brain that incapacitates gradually and you become less of who you were. You lose who you were. You become less...you do not lose who you are (female, husband with MCI).

[Alzheimer's is] The loss of self as others know you, as others knew you (female, husband with AD).

While diagnosed individuals defined AD in vague terms, and MCI with even less clarity, their spouses used far more medicalized terminology for both. As other studies suggest [66], many spousal support persons reflect broader cultural views when they assume diagnosed individuals experience a "loss of self." Consequently, carers envision the situation to be worse, or "harder," for them than it is for their counterparts. For example, many participants shared sentiments along the lines of this woman: "It's harder for me to perceive than for him to experience from what I gather because he is so content" (husband with MCI).

In contrast, diagnosed individuals discuss a "gradual," "normal," and "manageable" decline of memory perceived to be associated with aging and do not report distress over being diagnosed. For example, the following men depict their experiences accordingly:

PI: Is the diagnosis important to you? Diagnosed Husband: No. Wife: He's not broken up about it. PI: Is that because you think it is normal or do you think it is a disease? Diagnosed Husband: I'd go along those former lines. I'll tell you, as you get older why you forget; you have more things to remember. You remember the important things and throw out the things that aren't important. PI: So, you're not overly concerned? Diagnosed Husband: No (male, AD).

If you are drinking and smoking, that affects your memory. If you are just lazy and don't think about anything, you'll forget. I like to read. I like to study. I like to meet people and walk around. Keep my actions going (male, AD).

PI: So you feel like things are going well for you? Yes, I have no regrets of anything. We try to get out and do something every day (male, AD).

These findings are consistent with recent studies suggesting an inverse relationship between privilege—as regards social location along axes such as race, class, and gender—and negative views of dementia [72]. Diagnosed individuals in this study experienced their losses as less severe than their spouses perceived them to be, tending to see their symptoms as either "not a big deal" or a "nuisance" rather than "hellish." If diagnosed individuals fear being socially marginalized, then one might also expect them to minimize the significance of their condition to avoid being conflated with AD and

resist the subsequent social disenfranchisement [26, 27, 72]. Our data support previous studies recommending that carers follow the lead of those diagnosed and provide help as needed rather than preemptively [73].

Closely related, significant discrepancies also existed between diagnosed individuals and their spouses about the perception of the future:

PI: How do you see your future playing out?
 Husband: Fantastic. It's going to be all right. If you aren't dead, you aren't anything. That's all. Sure. I think I've been lucky at it so far. Because if you consider the percentage that make 80, it's a very small percentage probably.

Wife: It's a challenge. It's a problem. You've got a problem, you do what you can and you do not give up and you adapt. It's up to me to make myself happy, nobody else. I find things that give me what I need. Our life together is a challenge (husband, MCI).

As discovered elsewhere [36, 46, 74], these different reactions and interpretations potentially lead couples to experience the effects of memory loss in ways that can be incompatible. As a result of the different reactions, interpretations, and experiences within couples, according to both gender and diagnosis, previously harmonious "joint lived experiences" [28] within spousal dyads may be threatened [46]. In the joint career of memory loss, most of our dyads—in contrast—remained couple-focused, representing Kaplan's [36] "Til death do us part" or "We—but..." views. Despite this finding, the potential "compromised mutuality" [39] does pose a possible risk to the very interconnectedness and compassion of couples "working together" [75], which is integral to both providing and receiving high-quality, relationship-centered care. If we believe the potential for "couplehood" [33, 35–37, 63] to be unifying rather than dichotomizing between the personhood of each spouse separately, then it is important to understand these discrepancies and foster open dialogue and connection among the most intimate of social groups.

The only longitudinal ethnographic study of persons with Alzheimer's and their families that we are aware of presents strong evidence that caring relationships are "dynamic co-constructions built upon everyday events, interactions, environments, and disease progression" [59, page 335]. Accordingly, cooperative care relationships are built on foundations of mutual respect and sensitivity to persons with dementia whereas lack of trust and compassion leads to negative outcomes based on unrealistic expectations and retaliation efforts. If spousal carers do not perceive the work they are doing as "caregiving" but rather as an extension of their relational role, then a potential unintended consequence of the caregiver designation is to discredit the person with memory loss [76]. Our cross-sectional data support both the "co-constructive" nature of caring and the perception of so-called caregiving as an extension of their existing relationship rather than a new role, thus cultivating positive adaptations to memory-related changes and barriers

to in-home living for both parties. These data highlight the power of couplehood and significance of relationship status. It is important to account for potential costs/benefits of marital relationships since while we found a protective role of marital status here, relationships could instead pose a threat.

4. Discussion

To better understand the impact memory loss has on aging in place vis-à-vis intimate relationships, this article examined the efforts to maintain personhood and couplehood within spousal dyads confronted with AD or MCI. Informed by symbolic interactionism and social constructionism, data suggest that experiences of memory loss entail not only the perspectives of each spouse but also their shared relationship or "marital biography" [77]. By investigating the living-in-relationships of our dyads [77] and context awareness theory [35] in the "dynamics of dementia" [75], our data reflect the tremendous investment made by couples to preserve a working ("together") relationship. Our results reveal the complexity of dementia as something that is *shared*, for better or for worse, by offering an intimate understanding of the lived experiences of spousal dyads.

Our data support the conclusions of those who argue that in the "joint career" of Alzheimer's, couples exert considerable effort to construct a "shared awareness" [31], creating opportunities for diagnosed individuals and spouses alike to remain active in their relationship together [28, 63, 75] rather than being a one-dimensional, negative experience for both parties as previous studies and common social (mis)conceptions purport. These findings also suggest, however, that couples do not always share completely consistent perceptions of memory loss. Nonetheless, we contend that rather than being "disrupted" or "transformed" [46] in a pejorative or definitive sense, most couples in our study showed clear indications of "working separately" or "working apart" [75], or a "compromised mutuality" [39] that vacillates over time. Our data demonstrate that in some relationships, changes were quite purposeful since interaction requiring direct recall and/or shared memories or coping strategies grounded in interactional similitude may no longer benefit the relationship or be feasible. While we do not wish to downplay the fact that many couples ultimately find themselves "working separately" or "working apart," we acknowledge that these stages are not universal, linear, or entirely fraught and dismal. Contrary to Keady and Nolan's [75] argument that "working together" is the "best case scenario," the idea that "working" itself is couple-specific fits more closely with our data. Couples, either jointly or independently, managed to configure livable arrangements (i.e., find an "emergent fit") [78, 79] that do not always reflect congruence or shared worldviews, but there was a common commitment to "doing things together" [35] that disputes conceptions of "caregiving" or living with Alzheimer's in an exclusively disparaging or isolating light.

Although these data may represent one of the social (and personal) benefits of spousal relationships for aging in place; that is, positive dyad relationships and familiar environments, or "physical insideness" [6], are perhaps

protective against nursing home placement, it is important to highlight that there is a continuum of experience throughout this pendular process. Given that our respondents were all in the early stages of memory loss, their experiences are likely to change over time. Since awareness context theory is based on relational capacity and therefore negotiated [35], couples may go through any one component of awareness at a given period in their relationship and revisit phases as needed. Whereas “covering one’s tracks” [75] would mean that one member of a couple is in *suspended open awareness* and beginning to isolate, nowhere in our sample did we find couples in denial of the diagnosis, let alone in a relationship they cast as fraught or overwhelming. In contrast, couples that included one member who ignored, downplayed, or outright rejected the “master status” of diagnosis understood this as a means of coping and logical extension of enjoying life to the fullest rather than pathologizing it as “denial.” As has been reported elsewhere in the literature [28, 35, 58], individuals diagnosed with dementia (are forced to) work especially hard to avoid being conflated with their disease, a predictable consequence of a highly medicalized culture [27]. Our data demonstrate that their spouses work equally hard to support them in this.

The efforts to downplay AD/MCI reinforce recent discoveries that couples resist information on the disease and instead focus their energies toward positive thinking [35]. The humor and continued efforts at socialization, among other methods, reported by our respondents corroborate these findings. Several couples reported feeling at ease with so-called “symptoms” of memory loss and resultant life changes. Others (re)framed information-seeking as an attempt to achieve closure, confidence, and control over a disease that initially appeared foreign, overwhelming, and strictly negative. Engaging in such illness work is again highly couple-specific, with each pair (and perhaps individual within it) reacting differently. Accordingly, partners do not need to react the same way to be coping “well” as a couple. As reported elsewhere [72], the idiosyncratic nature of couplehood with AD means that a universal experience of the condition does not exist. Instead, the various experiences reflect the relative social positioning, or age, racial, ethnic, and class background, of the couples involved, here married, well-educated, middle-class, Caucasian seniors.

Our data also engage debates on dementia and the “self.” Existing studies posit that support persons engage in the bulk of restorative identity work *on behalf of those diagnosed* by reframing troubling symptoms as normal occurrences, downplaying their significance, or avoiding situations that would expose their loved ones’ shortcomings (or encouraging diagnosed partners to do so). The present data dispute this as the majority of our spouses proved highly adaptive to changes brought on by memory loss and negotiated meaning jointly with their diagnosed spouses. For example, in contrast to arguments that those with memory loss are unable to restore a familiar self [46], our findings show quite clearly that persons in the early stages of AD/MCI, too, are savvy, strikingly resilient, prove equally adaptive as their spouses, are decision makers, and are opinionated. Rather than a loss of personal identity, our

data suggest that as a result of the medicalized worldview dominant in contemporary society, it is the social self that is threatened by a diagnosis of memory loss. Our respondents further demonstrate (the need for) joint efforts to combat such social relegation [27]. This may suggest a limitation in our sample of relatively “privileged” people, both in terms of social location and severity of memory loss, who are afforded the luxury of addressing the “socioemotional” aspects of the condition rather than worrying about the difficulties in performing everyday instrumental tasks such as cooking, paying bills, and shopping that often accompany the condition [72] (While this may be due to a lack of diversity (i.e., marginalization) in the sample, the respondents are arguably underprivileged according to diagnosis and age. This interesting line of inquiry merits further elaboration but is beyond the scope of the present paper.).

In an effort to combat the “absence of self” rhetoric, many couples in our sample continued to maintain familiar social or recreational activities, or “social insideness” [6]. These interactions with the social world were meaningful and benefited persons with memory loss and their spouses, just as they would anyone else. By reconnecting couples with familiar, joint activities [53], appreciation for each other and ultimately “couplehood” can be fostered. While, of course, no amount of identity work can erase the biological effects of Alzheimer’s, our data demonstrate that a couple’s restorative strategies do much more than manage the other’s presentation of self [45]. That is, the paradox of working toward congruence in a relationship where one member is deteriorating does not stop couples from creating comfortable living conditions for each other and, in fact, in some instances it even engenders couplehood. Indeed, life with AD/MCI may shift spousal roles, but core elements of the identities of both individuals and the dyads they inhabit can be preserved and even strengthened.

Since meanings are socially constructed, the influence of memory loss will be different for every couple [32] and the joint production of meaning should be expected to shift over time. Through listening to the common threads among each couple’s unique story, the social bond of coupling can be better understood. In particular, our data support the belief that couples dealing with dementia together are more likely to remain positive, maintain a sense of self and couplehood, and evade the typically negative framework attached to dementia in America than might be the case for either party individually or single/widowed seniors generally. As reported elsewhere, spouses (can) play a crucial role in enabling persons with memory loss to remain at home [77]. Our findings thus challenge representations of memory loss as an exclusively negative and isolating experience and support existing research [56, 65] by demonstrating the strength of spousal bonds in helping both diagnosed individuals and their counterparts age well, maintain dignity and value, and remain in their homes for as long as possible. As others have argued [9], understanding how efforts to remain at home can support the preservation of self for persons with dementia warrants further study, including longitudinal analysis.

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Research Article

The Importance of Social Connectedness in Building Age-Friendly Communities

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The purpose of this paper is to further elucidate the importance of social relationships and social connectedness with aging in place and in developing elder-friendly communities. The process used in this study was inclusive of younger adults (age 40–65) as well as older adults (65+) in order to further understand how they envision a community that could support their own aging in place. A community forum, using the World Café format, was conducted in order to engage community members, 40 years and older, in conversation about the importance of social connectedness in elder-friendly communities. A second purpose of this forum was to obtain data on what would keep aging boomers in their community as they age. Three major themes emerged from qualitative analysis of the forum: *social reciprocity*, *meaningful interactions*, and *structural needs/barriers*. The results of this study reinforce the importance of social connectedness in creating and maintaining elder-friendly communities for older adults, as well as soon-to-be retired individuals, wishing to maintain life connectedness to their community. The study suggests the possibility of using more nontraditional research techniques (such as the World Café process) for gathering community level data.

1. Introduction

Increasingly, gerontological researchers, practitioners, policy makers, and planners are concerning themselves with the growing importance of aging in place. Aging in place does not have one single definition but broadly is considered to be the ability to continue to live in the environment of one's choice, even when declining competence reduces or threatens independence [1], while allowing for consumer choice in the types of services delivered [2]. Lawler [3] suggests that aging in place strategies can minimize inappropriate care and work best as a comprehensive and holistic approach to the needs of aging individuals and communities. Lau and colleagues [4] have conceptualized a framework for aging in place safely and acknowledge the importance of multiple factors, including the biological and psychological characteristics of the individual, the network of social support, formal services, the need for medical services, and the structure of the home and neighborhood. This and other frameworks clearly recognize

that aging in place strategies must consider not only the personal (micro) environment, including housing, but also community and structural components as well [4, 5].

2. Theoretical Frameworks

Before embarking on a discussion of elder-friendly communities, it is important to discuss a number of theoretical frameworks and conceptualizations from gerontology that help inform our understanding of aging in place. There are numerous frameworks that are relevant to aging in place including ecological theory, person in environment, and social inclusion/exclusion. In addition, the area of environmental gerontology has specific relevance to this discussion.

Ecological theory [6] suggests that there is a mutual relationship and mutual reciprocity between individuals and their environment and that this interaction occurs at multiple levels, including the micro-, exo-, mezzo-, macro-, and chronosystems levels [6]. Ecological theory is important

for the concept of aging in place as it suggests that individuals interact with multiple “levels” of environment in their day-to-day lives. Older people must not only interact with microenvironments such as their home and immediate family, but also with broader systems that can equally influence their ability to age in place. Another theoretical perspective that informs our discussion is that of person in environment [1]. This perspective, like ecological theory, acknowledges that the environment interacts with individuals at multiple levels and suggests that the environment is not a static backdrop but rather continually changes. From the person-in-environment perspective, the older person must continually take from the environment what he or she needs, control what can be modified, and adapt to conditions that cannot be changed [1].

Also of relevance to this discussion is the theory of social inclusion/exclusion. In social gerontology, the theory of social inclusion/exclusion examines the role of older people and highlights the social costs when individuals, families, or communities are excluded from or become disengaged from larger society due to characteristics such as poverty, gender, ethnicity, or neighborhood [7]. Scharf and colleagues [8] conceptualize the inclusion and exclusion of older people as associated with three key themes: participation and integration (beyond the labor market), spatial segregation, and institutional disengagement. Of particular interest in our exploration of aging in place is the thematic area of participation and integration. Scharf et al. [8] posit that participation and integration not only include older people’s involvement in community life, but also are associated with their social capital, including civic participation, and the nature of social networks and mutuality/reciprocity. An elder-friendly community can support these concepts.

In addition to several theoretical frameworks, the field of environmental gerontology has specific relevance to the topic of aging in place. Wahl and Weisman [9] suggest that environmental gerontology’s (EG) theories and findings can and should influence the development of age-friendly communities. For example, EG is concerned with the role of neighborhoods and the influence those neighborhoods have on opportunities and constraints of residents [10]. At a more macrolevel, EG recognizes the community as a locus of aging with a sociophysical and policy perspective [11].

With regard to elder-friendly communities, we can draw upon the work of Lawton [12] who posited that the environment has three major functions of maintenance, stimulation, and support [9]. Maintenance is concerned with the consistency and predictability of one’s environment, while stimulation is concerned with the effect of stimuli on behavior. Finally, support is concerned with the environment’s potential to compensate for diminished or lost competencies [13].

3. Elder-Friendly Communities

In recent years, the concept of elder-friendly communities has become central to the notion of aging in place. Described in various ways, an elder-friendly community is a place where “people can live their entire lives, if they so desire, rather than

having to relocate and lose their social capital” [14, page 6]. An elder-friendly community examines the environment in more macro-level terms as places where older people are actively involved, valued, and supported by an infrastructure that accommodates their needs [15]. In what was perhaps the first on-line conference focusing on elder-friendly communities, the Sierra Health Foundation suggested that elder-friendly communities are those communities in which age is not considered a barrier to improving lifelong interests and activities, where support and accommodations exist to meet the basic health and social needs of those with age-related disabilities, and where opportunities exist for older adults to develop new sources of fulfillment and engagement [16].

While the literature on elder-friendly communities is to a degree embryonic, several models have been developed in recent years. Among these models created in the United States, Canada, and Europe, the interrelatedness of social and structural factors is found to be consistently important. For example, Feldman and Oberlink’s [17] work on the *AdvantAge Initiative* demonstrated that elder-friendly communities must address basic needs, optimize well-being, maximize independence, and promote civic engagement. The City of Calgary Elder-Friendly Community Project noted that feeling safe, being valued and respected, staying active, and building community were important elements of an elder-friendly community [18]. The World Health Organization (WHO) has established international guidelines for age-friendly communities that include the encouragement of active aging by optimizing opportunities for health, participation, and security in order to enhance people’s quality of life as they age [19]. According to the WHO, an age-friendly city adapts its structures and services to be accessible to, and inclusive of, older people with varying needs and capacities.

While various models have emerged identifying aspects key to the concept of elder-friendliness, a consistent theme found in the literature is associated with social interaction or social connectedness. Scharlach [14] suggests that an elder-friendly community fosters both *connection* and *contribution*. An elder-friendly community will assist older adults to maintain social connectedness while deepening existing relationships. Such a community will recognize the social capital of these relationships that in turn result in *contribution*. The concept of contribution recognizes the wisdom and experience of older citizens and sees them as more than clients, but rather as active contributors to community well-being [14]. Similarly, The Calgary Project identified as important the active participation of older people in their communities. This premise is consistent with the work of Rubinstein and colleagues [20] who found that the ability to actively manage one’s environment was a source of well-being for older adults. Similarly, the model of age-friendly communities developed by the WHO clearly recognizes that social participation and social support are strongly associated with overall well-being, allowing elders to exercise their competence and enjoy the respect and esteem of their community [19]. Alley and colleagues [15] remind us that a community’s respect for older adults, which includes available opportunities, contributes significantly to their quality of life.

While social participation and connectedness are important in an elder-friendly community, there is a need for reciprocity between older adults and their community. For example, the *AdvantAge Initiative* [17] promotes the importance of civic engagement, including meaningful connections, volunteer and paid opportunities, and the prioritization of aging issues. The WHO acknowledges that an age-friendly community provides the option for older adults to continue to contribute to their community through civic engagement with both paid and volunteer opportunities and to have the ability to be active in the political process. The benefits of such reciprocity are many, such as an increased sense of purpose and satisfaction for older adults as they engage with the community, while younger community members may benefit from the knowledge and experience older adults bring to the community. As an example, intergenerational programs recognize the knowledge and skills possessed by older adults that can be shared with youth, while providing opportunities for civic engagement for the older person [1]. The key here is mutual benefit while recognizing that each segment benefits differentially.

Much of the research on elder-friendly communities has highlighted the multidimensional nature of community life and has not focused primary attention on social connectedness despite the importance of interdependence and engagement as primary qualities of aging in community [21]. For example, the *AdvantAge Initiative* identifies social and civic engagement but used quantitative measures to evaluate communities in three preordained realms [17]. Additionally, age-friendly community projects often obtain views from current elders. If an age-friendly community is a positive place to “grow” old, then the views of younger citizens (baby boomers, for example) need to be taken into account. Alley and colleagues [15] suggest that in an age-prepared community, processes of planning and advocacy are utilized to foster aging in place, which may be a prospective view of what is needed in planning for future community needs. This process must take into account the views and needs of the citizens who are not yet defined as older adults, but who will bring their own needs and views to the community.

The purpose of this paper is to further elucidate the importance of social relationships and social connectedness in developing an elder-friendly community. The process used in the project described here was inclusive of younger adults (age 40–65) as well as older adults (65+) in order to help understand how they envision a community that could support their own aging. Alley et al. [15] describe the importance of an “age-prepared” community [15, page 8] as one which has assessed its current services and is planning for the needs of future populations. Second, the qualitative methodology used in this study allowed for a more naturalistic and personal narrative. Padgett [22] acknowledges the importance of “meaning making” in the narrative process that includes storytelling, conversation, and discourse of naturally occurring speech. This study, therefore, was informed by the perspective of narrative analysis and the use of the spoken and written word in narrating the meaning of social connectedness as we age.

4. Background

In April of 2002, surveys related to assessing the elder friendliness of communities were completed by 5,100 individuals, 65 and over, throughout 10 cities across the United States [23]. In one participating community in Western Washington, a total of 514 surveys were completed. Findings suggested that older adults in that community were satisfied with their neighborhoods and participated in religious or cultural activities, and the majority of respondents were engaged in health screening [24]. The vast majority of these respondents had participated in some type of social activity in the past week and slightly fewer than one in three people volunteered [23]. The survey results were promising and positive, yet are now dated and do not reflect the opinions of members of the aging baby boom generation. Second, the original survey did not focus specifically on the issue of social connectedness but limited the focus to volunteering and participation in cultural and religious activities.

Recognizing the need to better refine and focus attention on the importance of social connectedness as part of elder-friendly communities, a city committee responsible for the continuation of the elder-friendly community agenda sponsored a community forum in October of 2009. A community forum using the World Café format [25] was conducted in order to engage community members, 40 years and older, in conversation about the importance of social connectedness in elder-friendly communities. Previous research in this area has approached the topic of social connectedness through an a priori definition of social engagement, primarily utilizing quantitative methods for measurement and evaluation [23]. This forum, however, sought to understand social connectedness from those approaching retirement using a more naturalistic method. A second purpose of this forum was to obtain data on what would keep aging boomers in their community as they age. The results of the forum and its applicability to elder-friendly communities and aging in place research are being presented here.

4.1. World Café as a Research Strategy. The World Café is a concept that was born out of *Appreciative Inquiry* [26], which is a form of research that emphasizes the positive aspects of an experience, particularly how that experience can foster creativity among people [26]. The World Café format involves exchanging ideas and sharing different points of view in a safe, intimate setting with the purpose of coalescing wisdom and experience into learning. A foundational component of the World Café concept is conversations, purposeful conversations that have a reason for taking place, “conversations that matter” [25, page 4]. They may be initiated to solve a community problem or to envision a preferred future, in this case an elder-friendly community, with a focus on social connectedness. The World Café format places an emphasis on moving from simply talking to taking action. This movement takes place as participants are able to understand the connection between talking and acting, or conversation as action [25]. It was in this context of “sharing collective discoveries” [25, page 138] that the community forum took place. This study provided

an opportunity to test the value of the World Café format as a method for future research.

5. Methods

This study was determined to be an exempt study by the University of Washington Human Subjects Division. The method employed for this study involved a melding of the World Café format as the structure of the study with a focus group format as the process that informed data collection in the study. Qualitative methodology was then used for data analysis. The data collection procedures differed from traditional focus groups in some significant ways. First, groups formed, discussed, and reformed with different participants for each of the three main questions that were posed at the forum. Second, instead of the more customary audio or video taping of the groups, each table was covered with paper on which participants wrote and/or drew as they discussed the topic at hand. These notes and doodles became the transcript along with notes taken by each table leader. This is consistent with narrative analysis in which both spoken and written words are used in meaning making [22]. Finally, groups were given great latitude as to how they addressed the discussion topic for their table. Some groups created action plans, and others were more reflective. The discussion leaders at each table helped to keep the group on topic and were careful not to inject their opinions into the group discussion.

The setting for the study was a community forum for those over 40 years of age living within the school district boundaries of a suburban community in Western Washington with a population of approximately 37,000, whose residents are predominately Caucasian (87%). Approximately 32% are ages 45 and over [27]. The forum included refreshments, and people were invited to sit at one of several round tables covered with paper for writing thoughts as they occurred to the participants. The conversation at each table began with the posing of one of three questions, with ample time allowed for each table group to discuss, strategize, and imagine a preferred future in an elder-friendly community. The three questions were as follows (1) What does it mean to you to be socially connected? (2) How can our city help with life transitions that would keep you in this community? (3) What do I have to offer my community? These three questions were developed through consensus by the city level committee charged with examining issues and processes that enhance an age-friendly community. The questions were designed to determine how people define and make meaning of being socially connected, to identify aspects of community life that would reinforce continuity with the community versus relocation to another community after retirement, and to ask participants to think about their own value to the community, thereby initiating thought around the idea of social reciprocity. Conversation was not limited to only the question at hand, and participants were invited to speak, draw, and write about the broader topic throughout the session. At set times, participants were asked to move to a different table, to be with a different group of people, and to consider a different question, until all three main

questions were answered by most of the participants. One member from each table stayed behind during the rotation in order to serve as an ambassador for the previous members, thus assisting in continuity of conversation. A goal was to allow participants to engage creatively as they tackled the questions together. So, rather than gather individual feedback, table leaders encouraged participants to converse with each other and to spend time thinking together about potential solutions to dilemmas as they were raised by group members. Once the group session was completed, participants were invited to gather into a large group to debrief and discuss the most important topics from the perspectives of the participants. This conversation was also guided, and notes were recorded.

5.1. Sample. A purposive sample of people over age 40 was recruited through newspaper ads and invitations from the city Parks and Recreation Department and through the Aging in Place Committee (AIP) membership. Membership lists from the Senior Activity Center and local faith communities also served as sources for potential participants. The invitation requested community members to participate in a community forum to discuss how to create, promote, and maintain a more elder-friendly community. Ultimately, 23 individuals participated in the community forum and ranged in age from midforties to late eighties. Participants therefore represented both those who might be identified as baby boomers as well as those who are currently retired and may be defined more traditionally as older adults. We did not collect specific data on age, but some participants offered their age as part of the conversations. The majority of participants were female and Caucasian. Since this was originally conceived by the AIP committee as a community forum and not a research project, no additional sociodemographic data were collected on socioeconomic status, education, or other typical variables associated with creating a demographic profile.

5.2. Data Analysis. Following the World Café community forum, researchers were asked to analyze the data from the event in order for the AIP committee to present findings and make recommendations to city government officials. No identifying information about participants was included with the data provided for analysis. Using an approach consistent with grounded theory [28], the researchers analyzed the data for common categories and themes. First, they met together and carefully reviewed the data from each of the questions. They used an open coding process for notes of verbal exchanges, drawings and notes from participants, and memos from group leaders. The few illegible writings and unrecognizable doodles were dismissed from the analysis process. As categories began to emerge, coding became more selective until three main themes were identified. Through-out analysis, the researchers engaged in conversation about meanings and interpretations, until they were satisfied they had a clear understanding of the data. In order to confirm that trustworthiness of the data was maintained, once the themes were identified, the AIP committee reviewed the findings and then invited all of the original forum participants to attend a focus group to discuss the findings. The focus

group was held in the same location as the community forum approximately two months after the forum was convened and was made up of five individuals (approximately 20% of forum members). Like the forum participants, most focus group participants were female and Caucasian, with one or two individuals representing communities of color. Focus group participants also ranged in age from early 50s to mid-70s. The focus group participants reviewed, clarified, and added data to the transcripts and confirmed that the themes identified by the researchers were reflective of the community meeting. The review by the focus groups provided credibility and trustworthiness (validity) to the qualitative findings, reinforcing a fit between the respondents' views and the researchers' interpretation as well as being confirmatory, for example, demonstrating that the study's findings were not imagined [22]. This process, known as member checking, not only serves to validate findings but is empowering to the participants and reinforces the close relationship between the researchers and the informants in qualitative research [22].

6. Results

The researchers identified three major themes that emanated directly from the data and were confirmed by the focus group. All three themes emerged from the open coding and were ultimately labeled as follows: *social reciprocity*, *meaningful interactions*, and *structural needs/barriers*. The three themes were identified and confirmed by both boomers and older participants.

6.1. Social Reciprocity. This theme was directly related to the overarching focus on social connectedness but illustrated the importance of added value in these relationships. Within the theme of social reciprocity, giving and receiving to/from one's community were both seen to be of equal importance. Some participants were currently volunteering or communicated an interest in doing so (giving). While exact ages were not available, it appeared that older adults (65+) were more likely to be active volunteers than their younger counterparts. Baby boomers expressed interest in volunteerism, while older adults may have already engaged in that process if they were interested. Many participants expressed an interest in receiving through such things as enhanced educational opportunities (e.g., more age-friendly options from the local community college and public university). The idea of educational opportunities at no or low cost was initially mentioned by younger participants. Participants also indicated that venues for creating social connectedness could come from both *formal* and *informal* entities. Formal entities are those which would require some infrastructure involving an organization or business, such as theater, outdoor concerts, or free movie nights. An example might be the initiation of social activities through city government, the local Chamber of Commerce, or even a local business. Informal entities would include activities that require limited resources, such as the creation of book clubs or neighborhood gatherings. Participants also suggested that such activities aimed at increasing social connectedness could be *sponsored* or *influenced* by community resources.

For example, through the Senior Activity Center, the city might sponsor a new boomer or senior walking group. Communities also could advocate for the development of social venues through influence. The city government, for example, could attempt to influence the policy of a not-for-profit community organization regarding how cumbersome and degrading the process is for older adults with limited income to obtain reduced membership fees.

Reciprocity between formal and informal systems could also occur. For example, a nongovernmental organization such as a church could recruit older volunteers from their congregation to volunteer in local schools. The theme of social reciprocity can and should conceptually occur at multiple levels, such as between governmental and non-governmental organizations, as well as between individuals and their community. In all aspects of the data, reciprocity (the mutual exchange of commercial or other privileges) was exemplified as the willingness to give and receive in order to foster social connectedness. No one suggested getting something for nothing. Inherent in the discussion of social reciprocity was the notion that the relationship between the individual older persons may occur at multiple levels of community and environment. Relationships and mutual exchange might occur at the level of neighborhood, a community organization, or at the level of city government or policy advocacy. For example, some forum participants suggested helping others by providing space for a communal garden (neighborhood), while some suggested that developing a volunteer position to work as a senior ombudsman related to negotiating city services would be beneficial to the whole (city government level). This exchange improves the well-being of those being helped while fostering a sense of accomplishment and service.

6.2. Meaningful Interactions. While participants discussed the desire to give and receive in order to maintain social connectedness, they were clear, however, that these experiences should be meaningful both to themselves and others. While a high number of forum participants expressed a desire to volunteer in their community, they clearly stated that the activity should be meaningful to them and important to the community. This sentiment communicates the view that these individuals see themselves as having social capital (whether or not it is recognized by others). Volunteerism was seen as an important way to give back to the community. As one participant put it, "we should all volunteer, even if it is in the home—respite, visitor, chores." The participants shared a collective view that the purpose of volunteering was not to kill time. Rather, participants were interested in sharing their passions, time, sense of history, and even sharing personal space to accomplish this end. One participant suggested that people share their gardens with others or help others to do crafts in their homes. Participants also viewed volunteering as a way they could advocate for others and for their community. Finally, if participants were to be involved in meaningful interactions through volunteering, they wanted to feel appreciated for the work they did. They voiced the concern that organizations often diminished or ignored the value of their time as volunteers and took volunteers for granted. It is

important to note here that forum participants did not suggest they wanted to volunteer for the sake of recognition, but rather they felt the need to be valued—not taken for granted. The message that was communicated by forum participants was that they desired both the organization/community in which they served as well as themselves to view their contributions as meaningful. While speculative due to a lack of specific data on age, the older participants appeared more settled in their roles as volunteers, as many of them had held these roles for some time. Younger adults (boomers) appeared to have more concerns about the meaning they derived from volunteer opportunities and how that may be accomplished.

6.3. Structural Needs/Barriers. While the majority of participants provided feedback on what or how they could contribute to their community to enhance social connectedness, a similar number of people voiced substantial frustration with the lack of either organized opportunities or communication with potential organizations with which to volunteer. These issues were impediments to social reciprocity as well as to meaningful interaction, and as such were labeled as structural needs or barriers. Structural (infrastructural) needs or barriers were those things participants viewed as currently lacking in the community but, if present, would facilitate social reciprocity both in terms of physical and social venues. For example, many forum participants expressed the need for improved methods by which potential volunteers could be connected to opportunities (community entities). These sentiments were expressed more strongly by younger participants. The examples that were given included organizations that needed volunteers should return phone calls more promptly to potential volunteers, as well as the need for more personal connections between those requesting volunteers and the people who might be willing to give of their time. Again, the importance of the value of time was communicated by the participants. They were not interested in having to make numerous inquiries to potential organizations in order to volunteer. The feeling expressed was that there was a lack of reciprocity from the very beginning on the part of agencies or organizations with which these individuals might wish to volunteer.

Transportation was described as an additional structural barrier and was mentioned frequently in all table conversations. Transportation was viewed as an essential element of social connectedness. In areas of both volunteerism as well as overall social connectedness, transportation issues associated with public transit and walkable communities were voiced. Issues concerning transportation included that a lack of reliable, frequent, and accessible transportation created barriers for participants within the community. As one individual said, “[a] lack of transportation isolates seniors.” The view communicated by these participants was that improved transportation can foster and enhance social connectedness by decreasing barriers of distance and reducing the need for use of one’s personal vehicle. One important distinction between younger and older participants was noted relevant to transportation. While younger participants voiced interest in improved transportation as a means toward improved social connectedness and as an environmentally friendly

alternative to automobiles, older participants expressed a more urgent need for improved transportation, as well as having a more specific personal need. For example, one couple who was likely in their 70s expressed the need for improved transportation services for their parents (in their 90s) as they identified gaps in transportation services as personally problematic.

7. Discussion

The purpose of this research project was to analyze data gathered from aging individuals (including baby boomers) on the importance of social connectedness in the creation of elder-friendly communities through a naturalistic method of inquiry. By engaging in a more naturalistic conversation utilizing the World Café format, the participants in the study were able to utilize conversation in meaning making without the confines of any a priori assumptions about social connectedness.

The findings from this community forum and the subsequent focus group reinforce earlier data from the original *AdvantAge Initiative* as well as other literature on elder-friendly communities and point to the utility of several important theories. First, these findings echo the original framework from the *AdvantAge Initiative* [17], which emphasizes the importance of social and civic engagement. The individuals from this community forum, as well as the elder counterparts in the original study, underscored the importance of meaningful connections to family, friends, and neighbors as part of civic engagement. An elder-friendly community needs to find new ways to promote active and continual engagement in community life. The findings from this study parallel the view of Scharlach [14] who suggests that as “we get older and ever closer to the end of our lives, maintaining social connectedness and deepening existing relationships becomes a priority” [14, page 9]. These findings also reinforce the importance of participation and integration, which is a critical element of social exclusion theory [8]. Forum participants identified multiple activities associated with social inclusion/exclusion including production (economic or socially valued) activity, political activity to improve or protect the social environment, and social activity that involved engagement with family, friends, and community. Scharf and colleagues [8] define participation and integration as “older people’s embeddedness in social networks and the extent to which older people contribute to or draw upon social capital that exists in their neighborhoods” [8, page 316]. Thus, our findings related to social reciprocity appear consistent with the major theme from social inclusion/exclusion theory. Our findings also reinforce the importance of Lawton’s [12] environmental function of support. A community needs to be dynamic in order to support changes in the older citizenry. While the concept of support is typically relevant to adjustment to altered or lost competencies, the concept of support can be extended to include the need for continued and changing modes of social and civic engagement.

This study also reinforces both the importance of volunteer opportunities and that those opportunities be

purposeful and meaningful. As suggested by Scharlach [14], in an elder-friendly community, older adults are not just seen as clients or passive recipients of services, but “active contributors to the well-being of the community” [14, page 9]. In the original *AdvantAge* survey, residents from this community volunteered at a rate substantially lower than the national average for the 10 *AdvantAge* communities [23]. What we learned from this study was that aging community members held interest and motivation to volunteer or otherwise be engaged in their community. We believe they see themselves as having social capital [29], but as Putnam [29] points out, others may not always share their view. The environmental function of stimulation [12] is relevant here as participants seemed to look to their community for stimuli for enhanced social well-being and to elicit new and relevant social and leisure behaviors [9]. Older participants appeared more likely to have volunteer and community activities in place, while younger adults (boomers) were perhaps seeking out methods for accomplishing that goal. Both younger and older participants also noted structural barriers to social connectedness and social integration, supporting Alley et al. [15] who suggest that while communities may be able to support aging in place, they may also contain barriers that make community living difficult for older residents. A recent study of 253 older adults reinforces the importance of organizational structure in volunteerism. Tang et al. [30] found organizational support (defined as choice of volunteer activity, training, and ongoing support) to be associated with socioemotional benefits, including perceived contribution and personal benefits. These researchers concluded that the “psychological well-being of older adults can be improved through engagement in meaningful volunteer activities and contribution to others” [30, page 603], again reinforcing what Rubinstein and colleagues [20] noted concerning the connection between well-being and active environmental management. In order for these benefits to occur, however, an elder-friendly community must work to eliminate structural and organizational barriers to volunteerism and social connectedness. As Scharf and colleagues [8] assert, participation and integration are enhanced by good public service such as access to reliable transportation. To not provide such services serves to reinforce the social exclusion of older people. The identification of structural barriers also reinforces the person-in-environment perspective that the needs of older people change over time and must be successfully navigated in order to maintain social integration. Lawton’s [12] environmental function of maintenance is relevant here. If a community is to be elder-friendly, the infrastructure needs to be consistent and predictable at the very least, while at the same time dynamic in its ability to provide stimulation and support.

Community-based research is particularly useful when it is able to identify problems and move toward a resolution of that issue. Researchers can partner with communities to study areas of interest, interpret results [31], and assist in the empowerment of community members to make changes [32]. The findings from this study have already resulted in community level change efforts related to volunteerism. An annual volunteer fair was initiated in 2010 with the goal of

creating a venue to match older volunteers with community level volunteer opportunities. This newly formed activity grew directly out of the identification of structural barriers in this research and was created through a partnership of senior advocates, the community’s AIP committee, and local organizations, including the area hospital. In the first year of operation, 30 community organizations and programs participated along with 120 attendees. More than 80% of older adults were successfully matched with local organizations, thus improving social connectedness, integration, and reciprocity in a direct and clear way. This event has now been established as an annual event sponsored by seniors, city government, and other community entities. Its goal is to improve civic engagement among older residents, thus fostering the connectedness between older residents and organizations that serve the community.

In addition to the importance of civic engagement, the philosophy of aging in place supports the continued importance of maximizing independence for not only the frail and disabled, but for aging adults of all abilities. In particular, these findings point to the need for accessible and available transportation, an issue that city officials and community advocates should attempt to improve through partnerships. As Feldman and Oberlink [17] noted in their original findings, “transportation and safety are fundamental factors that enable older adults to stay connected to the community” [17, page 5]. Rosenbloom [33] suggests that transportation in elder-friendly communities will need to be planned to provide more customized services, linking residential concentrations with important destinations, including volunteer opportunity destinations. The project findings noted that while all participants voiced the need for improved transportation services, the kinds of services desired may change with age. The lack of this kind of transportation was clearly identified as a major structural barrier reinforcing social exclusion and needs to be considered as future planning takes place. With impending cuts to public transportation, the aging in place committee is examining potential alternatives to improve transportation through private and voluntary means.

7.1. Limitations. The results of this study provide important information on social connectedness in elder-friendly communities. Still, this study has several limitations that must be acknowledged. First, as a qualitative and naturalistic study, the findings are the specific views of those individuals involved and cannot be generalized to any larger population of aging adults. Second, a further limitation is that those who responded to the invitation to participate in the community forum may have had a greater interest in the topic, or a vested interest in having their voices heard as compared to those who did not or could not attend. However, the study results provide a new dimension to the subject area and support previous studies and theories on aging in place, thus adding to the picture of what needs to be done to support the creation of elder-friendly communities. Because of the homogeneous makeup of forum participants, the voices of other communities such as communities of color were not clearly heard. It must be acknowledged that the opinions and

concerns of this group do not likely represent all older adults in this community. Finally, because sociodemographic data was not collected on individuals, distinctions between older (65+) and younger participants are based upon educated guesses about participant's age.

8. Conclusion and Implications

The results of this study reinforce the importance of social connectedness, participation, and integration in creating and maintaining elder-friendly communities and suggest that the findings are areas of concern not just for the old-old, but for recent and soon-to-be retired individuals wishing to maintain life satisfaction. The study suggests the possibility of using more nontraditional research techniques for gathering community level data such as the kinds of findings generated from the World Café process. While creating and fostering elder-friendly communities can be a long and ongoing process, small incremental change can occur from such studies as is illustrated by the case of the annual volunteer fair now established in this community.

If a national agenda of enabling our aging population to age in place is to be accomplished, creating elder-friendly communities has a logical and important role. Scharf et al. [7] suggest an important association between social connectedness and quality of life. They found that older people who rated their quality of life as "good" were less likely to experience social exclusion. For aging in place to happen successfully, with older adults being continually valued and integrated into community life, city officials, policy makers, and gerontological researchers will need to collaborate in order to move these ideas from research to reality.

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Research Article

Families, Friends, and the Neighborhood of Older Adults: Evidence from Public Housing in Singapore

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Introduction. This empirical paper examines how the Housing Development Board (HDB) public housing neighborhood influences older urban Singaporeans' social interactions and ameliorates social isolation. *Methods.* Using 4,542 observations of noninstitutionalized urban adults aged 60 and above, ordered logistic regressions are run to determine the predictors of isolation while controlling for physical health and demographics. *Results.* 87% of older Singaporeans reside in public housing apartments while 13% reside in private market housing. The main predictor of social isolation is living alone and the second main predictor is coresidence with adult children. The relationship between coresidence with adult children and isolation is mediated when controlling for older adult functional limitations. The public apartment neighborhood and daily participation in public neighborhood events have substantial effects on reducing the risk of isolation. Older adult contact with friends alleviates isolation more than contact with non-coresiding relatives. *Conclusion.* Findings suggest that the public neighborhood-built environment in Singapore plays a positive role in the social interactions of the elderly. Knowledge of the factors that decrease the risk of social isolation will have implications for studying morbidity and mortality among the elderly.

1. Introduction

In newly industrialized economies (NIE) in Asia, economic growth and demographic changes are leading to longer life and smaller family size. In Asia, given the Confucian beliefs of filial piety, it has been traditionally expected that the younger members of the family provide time, money, goods, and instrumental and emotional support for older adults. However, with later marriage and lower fertility, it is now more likely that older adults in Asian NIE have smaller families and a higher likelihood of living alone. As a consequence elders in urban settings may have fewer social interactions as they age. However it is not necessarily the case that late life is characterized by social isolation.

Individuals can adapt to the aging process with changes in their behavior and the environment. Older adults may compensate for a loss of social interaction when their families become smaller by interacting more with friends and neighbors who are in close physical proximity. This may especially be the case for the oldest old with functional limitations who may not only be neighborhood-based but neighborhood-bound. We hypothesize that in the Singapore

densely populated city state the built neighborhood environment contributes to older adult social interactions and ameliorates social isolation. Using state Housing Development Board (HDB) policy, we examine social interactions in the neighborhoods of older urban Singaporeans aged 60 and above.

Scholars studying the aging process have wrestled with the assumption that, in later life, an individual gradually disengages from society and inevitably becomes isolated [1]. However, it is posited that an older adult can choose to adapt the size of the social network and the quality of each contact. The composition and the extent of the social network of the spouse, children, friends, and neighbors can possibly change and be refined; this can vary for the young old and oldest old. To test our hypothesis, we are guided by the psychology theory of socioemotional selectivity by Carstensen et al. [2].

Most studies of social relationships in later life focus on the amount (e.g., number of individuals, frequency of contact) or content (practical help, advice) of social contact, not on individuals' perceived social isolation [3]. Isolation is often linked to a higher risk of worse health such as the risk of all-cause mortality, increased morbidity, depression,

and cognitive decline [4]. Subjective interpretations of social relationships are likely to be a key to understanding the impact of actual social connections on older adult health and well-being.

Based on the social-psychology disengagement theory of aging by Cumming and Henry [1], there is decreased interaction between the aging individual and others in the social system; but when disengagement is complete, the equilibrium which existed in middle age between the individual and his society will give way to a new equilibrium characterized by a greater distance and an altered type of relationship. This altered state is arguably isolation where the aged individual may be without any form of support. In contrast, socioemotional selectivity theory [2] states that as resources and energy decline in late life, older adults shed less intimate or rewarding relationships and increase their emotional investments in relationships that are more intimate or rewarding. In applying this theory to social networks, we argue that older Singaporeans can be motivated to selectively and actively engage with others in the social system. Disengagement and withdrawal from society in late life may not necessarily occur.

There are several aspects of social network connectedness that contribute to the ease of late life transitions and a lessening of isolation. One of these aspects is the number of direct ties to people and where some types of social ties may be more beneficial than others. There is the value of ties with kin members, who are likely to provide unconditional instrumental and emotional support [5, 6]. Another aspect is the value of close-knit social contacts in which the older person's contacts in a network know each other. This makes for a social network that enables the older adult's contacts to provide instrumental and emotional support, share caregiving duties, and pool resources.

For older adults especially the oldest old, due to debilitating health problems, neighbor interaction and neighborhood attachment may play a large role in their social networks. Older adults may be more vulnerable to the influence of their residential environment as they tend to travel outside their own neighborhoods less often than do younger adults and children who travel for work and school and tend to have a longer duration of exposure to neighborhood influences than younger individuals [7]. Being neighborhood-bound can then affect the older person's perceptions of the neighborhood. In a British cross-sectional population survey of people aged 65 plus living at home, Bowling and Stafford [8] find that individual perceptions of the area as neighborly and having good facilities are independently associated with lower likelihood of low social activities. Within the context of the city in the US, Subramanian et al. [9] find that a neighborhood with residential stability and a concentration of elders is positively associated with older person self-rated health.

2. Methods

We carried out an ordered logit estimation using the Singapore Social Isolation, Health, and Lifestyles Survey (SIHLS)

2009 cross-sectional data of 5,000 noninstitutionalized urban Singaporeans aged 60 and above. The SIHLS provides information on the older adult's extent of social isolation; health status and well-being; income, social engagement, housing, network support, and loneliness. The nationally representative survey data was collected using face-to-face interviews with older adults. Almost 90% of Singaporeans reside in HDB public apartment housing. The remaining 10% with higher household incomes reside in private housing.

The state agency HDB was established in Singapore to provide guarantees of housing for its citizens. The unchallengeable right to housing in the densely populated city state was achieved through the construction of affordable urban public housing which began in 1960. Public housing works started in 1960 when Singapore was still a British colony. In 1965, Singapore achieved Independence. From the 1980s, the HDB shifted its focus to building communities within self-contained towns. In spatial terms, because of close proximity, each HDB apartment building has become a neighborhood block; a cluster of neighborhood blocks has become an urban community equipped with social support services for the elderly and children and public spaces such as playgrounds, markets, and cafés, all with the aim of building a sense of place and community [10]. As life expectancy now for men is approximately 79 years and for women 84 years [11], there are increased interventions that promote aging-in-place such as day care and home care support services at the ground level of a HDB apartment block; apartments for the elderly with activities of daily living (ADL) limitations retrofitted with alarm buttons for emergency assistance; communal living for the oldest old without spouses or children; state subsidized senior activity centers that provide organized group activities. Based on HDB population level household survey interviews [12, 13] with residents, it is found that the longer the residence in the same neighborhood block and community, the greater the sense of belonging. This is especially for residents aged 55 and above with a length of residence that is 10 years or more. Thus, the older adult is likely able to maintain an intimate social network or build a stronger social network of family, friends, and neighbors.

HDB manages the public housing stock. This consists of approximately 90% of the total housing stock in the market. The monthly income of the household head that is below SGD\$8,000 (Singapore Dollar \$1 = US\$0.81) and the family size form the criteria of housing assignment to a given apartment. But this rule does not apply to the secondary or resale market. On the basis of this income threshold, each family is then allocated to a HDB apartment building block which consists of different built-up area sizes. Within each HDB neighborhood block, there is variation in household income from the lowest monthly income group of <SGD\$500 to the SGD\$8,000 threshold. The lowest income group resides in one-room HDB apartments, and the highest income group resides in four-room or five-room HDB apartments. Adult children starting their own homes have preferential access to an apartment that is in close physical proximity to their parents' apartment, which can then enable frequent contact.

Beyond this SGD\$8,000 monthly income threshold, individuals then purchase housing from the private housing stock which makes up the remaining 10% of the total stock. While higher socioeconomic status individuals aspire to switch from public housing to private housing, the vast majority of individuals particularly the younger age groups upgrade from smaller size HDB apartments to five-room HDB apartments [10]. The private housing stock consists of condominiums (gated communities with security and key card access), private apartments, bungalow houses, semidetached houses, terrace houses, and townhouses. Geographically, public housing and private housing are mixed because of land shortage in the island state. Public apartment buildings can be located next to private apartment buildings. However, public housing and state subsidized social activity centers are geographically concentrated. The care support services and social activity centers are within close walking distance for the elderly in public housing.

2.1. Data. Table 1 shows a description of the key variables that we used from SIHLS such as the outcome variable social isolation; residential type, composition, and size of the social network; age and covariates including physical health and demographics.

For the outcome variable of perceived isolation, respondents were asked “How often do you feel isolated from others?” This subjective measure is on a scale of 1–5, 1 = lowest level, and 5 = highest level. In our analysis, we study the social network as an interaction between the social network and feelings of isolation change. As physical health is an age-related factor, we wanted to control for physical health and assess whether the association between the social network and isolation holds. The physical health measures that we used were difficulties with activities of daily living (ADLs) which refer to self-care tasks and instrumental activities of daily living (IADLs) which refer to the ability to carry out activities associated with maintaining a household. For ADL limitations, respondents were asked the number of difficulties they had with the following activities: (1) take a bath/shower, (2) dress up, (3) eat, (4) transfer stand up from a bed/chair, (5) walk around the house, (6) walk outside of the house, (7) use a squatting toilet, and (8) use a sitting toilet. For IADL limitations, respondents were asked the number of difficulties they had with the following activities: (1) prepare own meals, (2) leave the home to purchase necessary items or medication, (3) take care of financial matters such as paying utilities, (4) use the phone, (5) light housework, (6) take public transport to leave home, and (7) take medication as prescribed.

2.2. Empirical Specification. The aim is to understand how social interactions taking place within the HDB neighborhood environment may decrease isolation. The relationship between the HDB-built environment and perceived isolation may be operating through the older adult’s perception of the neighborhood. Bowling and Stafford [8] found that individual perceptions of the area as neighborly and having good facilities are independently associated with lower likelihood

of low social activities. In our empirical specifications, we included the explanatory variable of daily participation in HDB neighborhood events as a proxy for neighborhood perception.

Using our cross-sectional data, we first start by gaining an understanding of the distribution of social interactions with non-coresiding kin members and nonkin members. We would like to understand how the elderly choose to interact with social contacts outside of the home and how this changes with age. If contacts outside of the home are intimate and rewarding relationships, we hypothesize that the elderly will make more of an effort to stay connected. We then compared this with the distribution of social interactions for older adults in private housing. For these distributions, we used locally weighted bivariate regressions and we did not control for health. From these bivariate regressions, we then explored in depth the composition of the social network consisting of family within the home and non-coresiding relatives, friends, and neighbors outside of the home using multivariate regression.

Multivariate regression techniques were used for generating estimates of perceived isolation. We first regressed the measure of perceived isolation on the variables, HDB residence, participation in HDB neighborhood events, household size, whether the older adult is widowed, whether the older adult lives alone or coresides with a child/children, and age. The focus is on how the older adult’s relationships with the family within the home and residence area vary with isolation. The explanatory variable, participation in HDB neighborhood activity is a proxy for the older adult’s neighborhood perception. If the older adult perceives the neighborhood favorably, then there is a high likelihood of participation in social activity within the neighborhood. Because of data limitations we were unable to add a variable for length of residence in the same neighborhood.

We then proceeded to factor in the social network of non-coresiding relatives including children, friends, and neighbors who are outside of the home. The social connectedness of non-coresiding relatives and friends was specified as the interaction between the number of individuals connected and the frequency of contact each month. Types of contact include face-to-face visits in the home and outside of the home and phone calls. We did not specify such an interaction for neighbor connectedness because of data limitations. The covariates used were physical health, income, gender, and ethnicity. Physical health is an age-related factor in terms of functional limitations that deteriorate with age. We present a likelihood ratio test to determine if the covariates make a difference to the outcome when not included.

3. Results

Using kernel regressions, Figures 1 and 2 show the age for distributions of social interaction among non-coresiding relatives, friends, and neighbors by HDB housing and private market housing. They provide useful information on the pattern of social interactions outside of the home which is important to consider for the elderly with physical mobility

TABLE 1: Description of variables.

Variable	Description	
Social isolation	“How often do you feel isolated from others?”	Never = 56.6%, Rarely = 30.7%, Occasionally = 9.5%, Fairly Often = 2.3%, Always = 1%
Residence in HDB housing	The respondent resides in HDB public housing	Yes = 87.3%, No = 12.7%
Daily participation in a HDB neighborhood event		Yes = 78.1%, No = 21.9%
Network Composition and size	The respondent is widowed	Yes = 35.5%, No = 64.5%
	The respondent lives alone	Yes = 5.8%, No = 94.2%
	The respondent lives with children	Yes = 69.6%, No = 30.4%
	“If you live with your children, what is the household size?”	Mean = 4.2, SD = 1.6
	“Among all your relatives not living with you (including children and grandchildren), how many relatives do you see or hear from at least once a month?”	0 relatives = 14.7%, 1 relative = 4.1%, 2 relatives = 12.5%, 3-4 relatives = 26.9%, 5-8 relatives = 23.9%, ≥9 relatives = 17.9%
	“Among all your friends including those who live in your neighborhood, how many friends do you see or hear from at least once a month?”	0 friends = 14.7%, 1 friend = 3.6%, 2 friends = 14.1%, 3-4 friends = 30.7%, 5-8 friends = 14.9%, ≥9 friends = 22%
	“Among all your neighbors including those you consider your friend, how many neighbors do you see or hear from at least once a month?”	0 neighbors = 11.1%, 1 neighbor = 10.1%, 2 neighbors = 21.8%, 3-4 neighbors = 36%, 5-8 neighbors = 12.4%, ≥9 neighbors = 8.6%
Frequency of Contact within Network	“How often do you see or hear from relatives with whom you have the most contact?”	Never = 5%, Seldom = 11.6%, Sometimes = 25%, Often = 36.9%, Very Often = 12.5%, Always = 9%
	“How often do you see or hear from friends including those who live in your neighborhood with whom you have the most contact?”	Never = 13.2%, Seldom = 12.6%, Sometimes = 27.7%, Often = 32.8%, Very Often = 7.7%, Always = 6%
	There is no question in the survey on the frequency of contact with neighbors including those considered as friends	
Age		Min = 60, Max = 101 Mean = 72.8, SD = 8.1
Income	Household monthly income (Singapore Dollar \$1 = US\$0.81)	Less than S\$500 = 9.5%, S\$500–S\$999 = 14.6%, S\$1,000 to S\$1,999 = 24.6%, S\$2,000 to S\$2,999 = 15.9%, S\$3,000 to S\$3,999 = 6.2%, S\$4,000 to S\$4,999 = 2.8%, ≥S\$5,000 = 3.2%, refuse to respond = 3.2%, do not know = 20%

TABLE 1: Continued.

Variable	Description	
Physical health	Self-rated difficulties with the following eight ADLs: (1) take a bath/shower, (2) dress up, (3) eat, (4) transfer stand up from a bed/chair, (5) walk around the house, (6) walk outside of the house, (7) use a squatting toilet, and (8) use a sitting toilet	0 ADL difficulty = 62.7% 1 ADL difficulty = 13.6% 2-3 ADL difficulties = 12.7% ≥4 ADL difficulties = 11%
	Self-rated difficulties with the following seven IADLs: (1) prepare own meals, (2) leave the home to purchase necessary items or medication, (3) take care of financial matters such as paying utilities, (4) use the phone, (5) light housework, (6) take public transport to leave home, and (7) take medication as prescribed	0 IADL difficulty = 82.5% 1-2 IADL difficulties = 8.5% ≥3 IADL difficulties = 9%
Gender	The respondent is female	Female = 54.9%, Male = 45.1%
Ethnicity		Chinese = 71.52%, Malay = 17.08%, Indian = 10.22%, Other ethnicities = 1.18%

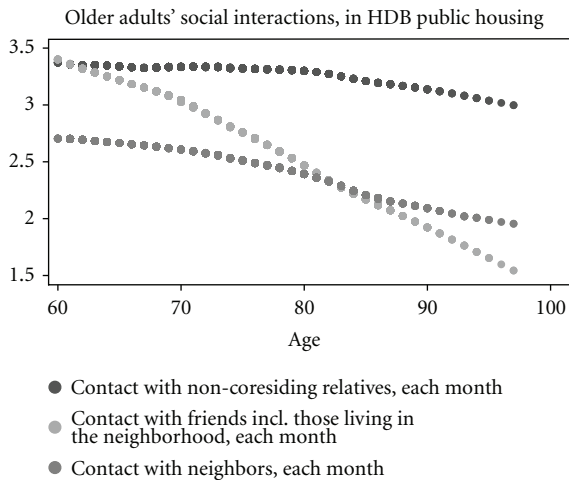


FIGURE 1: These locally weighted bivariate regressions do not control for health.

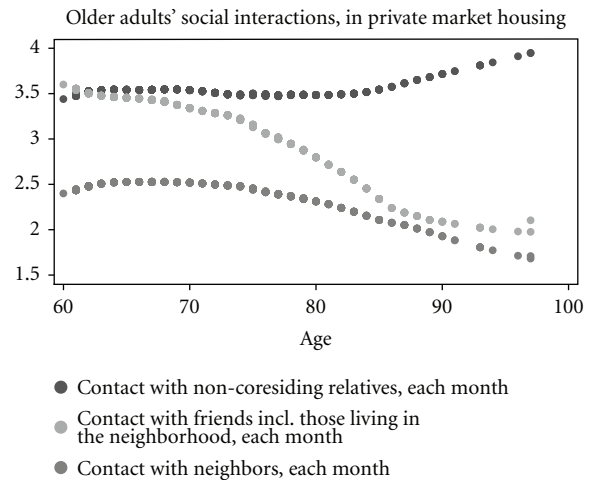


FIGURE 2: These locally weighted bivariate regressions do not control for health.

that deteriorates with age. Contact with non-coresiding relatives remains at relatively high levels across age. A decline of contact with friends and neighbors starts within the range of age 70 and 80, and the decline is sharpest for contact with friends, including those who live in the same neighborhood. The decline is sharper for those in a HDB neighborhood than for those in private housing. However, Figure 2 shows that for individuals from the mid 80s to 100, contact with neighbors in HDB housing falls at a slower rate than contact with friends. The oldest old in public housing appears to substitute neighbors for friends.

From Table 1, mean age of respondents is 72.8 years and 54.9% of them are women. 12.7% report suffering from isolation occasionally, fairly often, or always. 35.5% are widowed, and 5.8% live alone. 87.3% reside in HDB public housing, and 78.1% report daily participation in HDB neighborhood events. 76.7% report that they have monthly contact with three or more relatives. 58.2% report that they

often, fairly often, or always see or hear from close relatives. 67.5% report that they have monthly contact with three or more friends including friends who live in the same neighborhood. 46.6% report that they often, fairly often, or always see or hear from friends. 56.9% report that they have monthly contact with three or more neighbors who may not necessarily be friends.

Table 2 provides the predictors for perceived social isolation using ordered logistic regressions. The predictors are expressed as coefficient effect sizes, β . The first model (1) does not include the social network outside the home or covariates. (2), (3), (4), and (5) include the social network outside the home and covariates. The different contacts that make up the social network are added stepwise across (3), (4), and (5). In the first model, (1) which excludes the social network outside the home, the strongest predictor of isolation is living alone ($\beta = 0.683, P < 0.01$). Similarly when household size is smaller, there is a higher likelihood

TABLE 2: Marginal effect coefficients from ordered logistic regression models predicting older adult perceived social isolation.

	(1)	(2)	(3)	(4)	(5)
Residence in HDB	-.169** (.086)	-.162* (.087)	-.186** (.087)	-.209** (.088)	-.219** (.088)
Daily participation in HDB neighborhood events	.008 (.006)	-.114 (.070)	-.100 (.070)	-.164** (.071)	-.160** (.071)
Living arrangements					
Household size	-.165*** (.022)	-.140*** (.022)	-.138*** (.022)	-.139*** (.022)	-.139*** (.022)
Widowed	.137* (.071)	.210** (.079)	.200** (.079)	.197** (.080)	.199** (.080)
Residing alone	.683*** (.134)	.680*** (.134)	.615*** (.135)	.652*** (.135)	.655*** (.135)
Coresiding with adult children	.332*** (.082)	.247** (.083)	.248** (.083)	.234** (.084)	.230** (.084)
Social network					
Relatives incl. non-coresiding children			-.023*** (.004)	-.010** (.005)	-.012** (.005)
Friends				-.035*** (.005)	-.037*** (.005)
Neighbors					.040 (.024)
Age	.011** (.004)	.003 (.004)	.003 (.004)	-.0007 (.0044)	-.0006 (.004)
Covariates	No	Yes	Yes	Yes	Yes
Observations	4,542	4,542	4,542	4,542	4,542

Notes: *** $P < 0.01$, ** $P < 0.05$ and * $P < 0.10$. The covariates are physical health limitations—ADL and IADL, income, gender, and ethnicity. The likelihood ratio test for the restricted model without the covariates and the unrestricted model with covariates shows that there is no variation in the main coefficients of interest—HDB residence, daily participation in HDB neighborhood events, family living arrangements, and the social network. LR $\chi^2(4) = 336.02$. Prob $> \chi^2 = 0.0000$.

of perceived isolation ($\beta = -0.165$, $P < 0.01$). From this model the second strongest predictor of isolation is whether the older adult coresides with adult children ($\beta = 0.332$, $P < 0.01$). However, when physical health and demographic controls were added, the effect of coresidence with adult children on increasing isolation weakens ($\beta = 0.247$, $P < 0.05$).

In terms of whether isolation increases with age, we found a relatively small positive effect ($\beta = 0.011$, $P < 0.05$) in the first model (1). The effect size of age remains very small even when the social network is incorporated and even after controlling for physical health, income, and demographics. See models (2), (3), (4), and (5).

Next, we focused on predictors of lower isolation. From model (1) in Table 2, older adult residence in HDB public housing ameliorates the likelihood of perceived isolation ($\beta = -0.169$, $P < 0.05$). The HDB coefficient effect size remains strong and statistically significant across models (2), (3), (4), and (5). We attempt to explain the relationship between HDB neighborhood and isolation through older adult daily participation in HDB neighborhood social activities via models (4) and (5) when contact with friends is added. From (4), daily participation in social activities in the HDB neighborhood has a substantial effect on lessening isolation ($\beta = -0.164$, $P < 0.05$). There is a similar coefficient effect size in (5). From (4) controlling for other variables, contact with friends has a positive effect on lessening isolation ($\beta = -0.035$, $P < 0.01$). There is a similar coefficient effect size in (5).

4. Discussion

The results show that the strongest predictor of isolation in old age is living alone. Unexpectedly, the second main predictor of isolation is coresidence with children. This result is somewhat surprising as it is traditional Singaporean practice for older adults to coreside with children and to some extent grandchildren. The positive association between coresidence with adult children and isolation has some similarity to studies on the determinants of older adult subjective well-being. In a review of sociological and psychological studies on aging and well-being, George [14] finds that interacting with adult children appears to have a weak or nonexistent relationship with subjective well-being. But from our findings, the relationship between living with adult children in old age and isolation is mediated when there is consideration for the older adult's functional limitations. The extent of ADL and IADL limitations may increase their dependency on coresiding children for instrumental support and assuage perceived isolation.

The strongest predictors for decreasing the likelihood of isolation are in order, residence in HDB public housing and daily social participation in HDB neighborhood events. The elderly are very likely to view their HDB neighborhood favorably because of the availability of social care and support services and public spaces for social interaction. The HDB built environment may then be perceived as conducive for social contact for the elderly who are neighborhood-based and neighborhood-bound. In contrast, growing old

in private condominiums which are gated communities or bungalow houses that are fenced off may inadvertently create a sense of being cut off from society.

The social network of non-coresiding relatives and the elders' friends also has influence on reducing isolation. In comparing the relationship between the different social contact types, contact with friends has a far more positive effect on alleviating isolation compared to contact with non-coresiding relatives including children. Contact with neighbors does not have any effect on perceived isolation. From the literature on elderly subjective well-being, George [14] summarizes studies that show that friends are generally more important for subjective well-being in later life than are relationships with children or other relatives. Friendships that are sustained in late life may be more intimate as the elderly grow old together and reminisce about the rapid modernization of Singapore over the span of 46 years.

Following the application of socioemotional selectivity theory to social networks, we have provided some understanding about the predictors for reduced social isolation among Singaporean elderly. The HDB neighborhood environment plays a positive role in the social interactions of the elderly who are neighborhood-based and neighborhood-bound. Knowledge of the factors that decrease the risk of social isolation will have implications for studying morbidity and mortality in old age. But the cross-sectional nature of the data limits our analyses in that we are unable to directly assess how individuals transition into late life and how behavioral adaptation and isolation vary as the young old become the oldest old. Also, we are unable to make clear arguments for causal relationships or to fully distinguish between age and cohort effects.

Appendix

See Tables 1 and 2

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Research Article

Aging in Place: Evolution of a Research Topic Whose Time Has Come

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Over the past 30 years, policy makers and professionals who provide services to older adults with chronic conditions and impairments have placed greater emphasis on conceptualizing aging in place as an attainable and worthwhile goal. Little is known, however, of the changes in how this concept has evolved in aging research. To track trends in aging in place, we examined scholarly articles published from 1980 to 2010 that included the concept in eleven academic gerontology journals. We report an increase in the absolute number and proportion of aging-in-place manuscripts published during this period, with marked growth in the 2000s. Topics related to the environment and services were the most commonly examined during 2000–2010 (35% and 31%, resp.), with a substantial increase in manuscripts pertaining to technology and health/functioning. This underscores the increase in diversity of topics that surround the concept of aging-in-place literature in gerontological research.

1. Introduction

Over time, the goal of aging in place has become a focal concept by policy makers as well as researchers in their collective efforts to create communities that facilitate the widely recognized preference by a majority of older adults to remain in their homes and communities as long as possible [1–4]. Efforts to reform how and where long-term care services are provided have produced substantial programs enacted to reduce reliance on the most expensive forms of care to address disability associated with chronic disease and impairment. A shift in priorities and resources toward deinstitutionalization has resulted in explicit policies and programs that reflect a paradigm shift from nursing homes as the most likely alternative for older adults requiring multiple services to nursing homes as an option of last resort.

Corresponding to greater policy aimed at facilitating aging in place, there has also emerged a growth in academic literature, reflecting the concerns of stakeholders (including policy makers, care providers, families, and older adults

themselves), which illuminates a greater number of options aimed at stemming rising costs of care, and accommodating and facilitating the wishes of older adults to remain independent. Initial efforts to conceptualize and define aging in place as an important discussion topic focused on understanding older adults in terms of changes occurring both in themselves and in their surrounding environments. For instance, in describing the concept of environmental press, Lawton and Nahemow [5] examined dynamic interactions between housing environments and the physical capabilities of older people. In optimal settings, characteristics of the environment should function to accommodate losses of physical function. Thus, Lawton recognized the necessity of a variety of specialized living environments that could address the full range of functioning from independence to dependence on institutional care, with community housing, congregate housing, and boarding homes falling within this spectrum. Since this early seminal work, concepts of aging in place evolved to emphasize services and technology as important contributors to an older adult's ability to remain in his/her

home. Indeed, Brink [6] highlighted the importance of integrating services with housing in stating that the goal of aging in place would be seriously hampered if support services are unable to keep up with their demand. Consistent with Lawton's [5] view, the primary goal of services and technology is to match the level of support provided by the housing environment to the level of capabilities (or need) of the individual.

Over the past 30 years, policy makers and professionals who provide services to older adults with chronic conditions and impairments, as well as researchers, have placed greater emphasis on conceptualizing aging in place as an attainable and worthwhile goal. Nevertheless, there is little known of the changes over time in the attention given to aging in place within gerontological literature. With respect to the quantity and substance of the literature on aging in place, the current study was designed to provide important insight as to the prominence of environmental, service based, technology, and health factors associated with an older adult's ability, inability, or choice to age in place. Moreover, given the increasing number of older adults who express a preference to remain in their home, understanding and tracing the evolution of this topic in gerontology is more timely today than ever before. Perhaps more importantly, in studying changes in empirically based aging in place publications, light can be shed on how such temporal changes may influence policy related to services, environment, and technology.

In our analyses, we examined the trajectory of aging in place within the context of scholarly discussions in major gerontology journals. Specifically, the purpose of our research was to examine how the literature on aging in place has changed over time in highly visible gerontology journals, with a focus on analyzing trends related to the amount, location, and variety of research topics. We hypothesize that generally there would be an increased proportion of articles dedicated to the topic of aging in place, and that among those articles, the diversity of topics covered in publications would increase over time.

2. Methods

In this study, we analyzed scholarly articles published from 1980 through 2010 in eleven leading gerontology journals with content areas that focus on research and/or policy pertaining to older adults. In a preliminary analysis, we examined a broad array of terms that capture the concept of aging in place. These included aging/ageing in place, aging/ageing at home, naturally occurring retirement community(s), elder friendly community(s), aging in the community, home independence, and staying put. For the terms that yielded less than 20 manuscripts within our 1980–2010 timeframe, we excluded these terms from our final search list. This left 3 critical search terms: aging/ageing in place, aging/ageing at home, and naturally occurring retirement community(s). Given that our interest was in examining trends in aging in place, we operationalized our definition of aging in place search items to include only the most commonly used terms. This approach results in a more conservative estimate of documenting trends in aging in place; nevertheless, given the

minimal number of manuscripts that utilized the alternate terms pertaining to aging in place, this criteria should not substantially bias our results.

Journals were chosen based on the frequency of appearance of the 3 critical terms and their variations (aging/ageing in place, aging/ageing at home, and naturally occurring retirement community(s)) in a preliminary search using Google Scholar. If terms appeared in each journal 20 or more times during the 30-year period of interest, we included the journal in our main analysis. These journals included *Ageing & Society*; *Ageing International*; *Generations*; *The Gerontologist*; *Journal of Aging and Social Policy*; *Journal of Applied Gerontology*; *Journal of Gerontological Social Work*; *Journal of Gerontology*; *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*; *Journal of Housing for the Elderly*; *Research on Aging*. Next, the sum total of all articles for each journal and a grand total number of articles were calculated. These totals were used to compute the proportion of articles dedicated to the topic of aging in place over time. Retrieved articles were excluded from analyses if their contents were book or audiovisual reviews, conference abstracts, or editorials. Finally, we used the advanced search option on each journal's official website, where possible, to identify articles containing any of the three exact phrases and their variations in titles, abstracts, key words, or in the bodies of articles—articles were not counted in this step if key terms appeared only in the bibliographies of papers. For journal websites without this advanced search option, the advanced search option under Google Scholar was used for searching within the specific journal. A similar approach was used by Carr and colleagues [7] in their review of arts and aging research.

Articles that were retained were coded according to three criteria. First, articles were sorted according to whether their content dealt directly with the concept of aging in place (direct) or whether key terms were mentioned only in passing in articles primarily about other topics (indirect). Next, we indicated whether aging in place articles were focused on five areas that influence the capacity of older adults to age in place—these included subcategories for housing/environmental considerations (e.g., neighborhood characteristics and home modifications); community/social services (e.g., influence of church groups, barriers to access of services); assistive devices/technology (e.g., telemedicine, remote assessments, and silver alerts); health and functioning (e.g., supportive housing for frail adults); a miscellaneous category that contained factors that did not fit into the other four subcategories, such as issues pertaining to migratory patterns or municipal zoning regulations. Any single article could be categorized in one or more of these topic areas, depending on the range of scope of the article. Finally, we sorted articles by whether the content was primarily research oriented, or whether articles discussed policy pertaining to aging in place. Articles were categorized as research oriented if concepts of aging in place were analyzed empirically as an antecedent (an independent variable), a mediator (a process variable), or an outcome (a dependent variable). Articles were categorized as policy oriented if their content

discussed program development or implementation of programs where aging in place was a stated goal.

The search and review of manuscripts were conducted by two readers (SV and BAS), who determined the criteria for inclusion and categorization of manuscripts prior to review. Each reader independently reviewed the possible manuscripts. When the readers disagreed on the categorization of any article, disparate cases were discussed and an agreed upon consensus for classification was established and recorded, before data were analyzed. We conducted frequency analyses and computed the proportion of aging in place articles relative to the total articles published during the period of interest. We also conducted frequency analyses differentiated by whether articles mentioned aging in place as an indirect concept, or whether aging in place was the central issue discussed by the article (direct concept). Finally, we calculated the frequency of aging in place articles by subcategory topic (i.e., whether articles addressed housing, services, technology, health, and/or some other topics), and by whether articles were research focused or policy focused.

3. Results

Among the journals examined, there was an increase in the publication of aging in place manuscripts from 1980 to 2010 (Figure 1(a)). During the 1980s, very few publications included this concept. The number of these articles nearly doubled in the 1990s, and a marked increase in the absolute number of manuscripts pertaining to aging in place began in 2001, with the highest number of publications in the most recent year of 2010. The initial inclusion of “aging in place” in the literature (1980s) generally mentioned this concept indirectly, and it became a central part of some published articles in the 1990s, where the ratio of direct to indirect mention was about 0.55. From 2000 to 2010, this ratio of direct to indirect mentions increased to 0.75, with an excess of direct mentions relative to indirect mentions published in 2001 (ratio: 1.22). During the overall 1980–2010 period, nearly 70% of all aging in place manuscripts indirectly mentioned this concept.

When we considered the number of aging in place publications relative to the number of overall journal publications (Figure 1(b)), the trends over time were remarkably similar to the absolute number of aging in place manuscripts (Figure 1(a)). This suggests that the proportion of aging in place articles has increased over time. Aging in place articles have also expanded in the diversity of the topics covered (Figure 1(c)) from 1980 to 2010. In the earliest decade (1980–1989), environment and the “other” category (including mostly articles pertaining to migration) dominated the aging-in-place literature. Over the following ten years (1990s), aging in place manuscripts extended to areas of service, and there was some mention of health and functioning. During this time, topics related to the environment remained a leading area of focus for aging in place publications. The 2000s marked a time of increased breadth of topics covered among the aging-in-place literature. The topic of the environment and services were the most commonly examined areas during the period

2000–2010 (35% and 31%, resp.), with 15% of the articles pertaining to health and functioning and 10% representing the “other” category. Articles related to technology became more prominent during the 2000s, representing 9% of aging-in-place publications. When we examined the entire 1980–2010 time frame, this trend resembled that of the lattermost decade: environment (36%), services (29%), health and functioning (15%), other (13%), and technology (7%).

Upon classifying articles as empirical research based and/or explicitly pertaining to or mentioning policy, we noted an increasing absolute number of both empirical and policy-related articles over time (Figure 1(d)). Interestingly, the proportion of research-based to policy-related articles markedly increased between the 1990–1999 and 2000–2010 period. During 1990–1999, research articles were nearly 1.5 times as prevalent as policy-related manuscripts. This ratio increased over the 2000–2010 timeframe, where the proportion of research to policy articles on aging in place was 2.5.

Our initial efforts to determine how aging in place has developed over time and across topics have yielded a number of important points. Of note in our analyses was the increase over time of the “other” category, which was comprised mostly of issues surrounding older adult migration between regions in the US, concerns surrounding older immigrant adults, and municipal-level factors, such as zoning regulations. In addition, we noted four other important trends in the literature that affect the ability of older people to age in place. First, aging in place publications span a wide spectrum ranging from broad to specific investigations. Some broad depictions of manuscripts discuss this concept within the context of the worldwide greying of our communities [8] and exploratory, qualitative analyses (e.g., determining the amenities that individuals currently utilize to age in place [9]). The more specific papers on aging in place focus on services (e.g., nursing homes and assisted living facilities [2], health monitoring [10], housing and social support [11, 12], and palliative care [13]).

Second, with respect to the environment, aging in place has two prongs: aging in place in the home and in other structured settings in the community. While the definition of “home” varies (e.g., single or multiple family home) and continues to remain an essential component of aging in place, increasing attention has highlighted the importance of community care as a means to either support aging in place or as an initial step in fostering the goal of aging at home [14, 15].

Third, aging in place is not a one-size-fits-all concept. There are multiple issues surrounding differences in aging in place among diverse populations. Such diversity arises from differences in preferences and access to services with regards to differences in rural versus urban settings [16, 17], income [18], orientation (e.g., lesbian, gay, bisexual, and transgender sensitivities [19]), older adults with special needs (e.g., intellectual disabilities [20] and prisoners [21]), older adults with special circumstances (e.g., adults who are caring for children with developmental disorders [22]), more general differences in eastern versus western views on aging in place [23], and broad international differences in services that individuals require, want, and need [24]. Regardless of

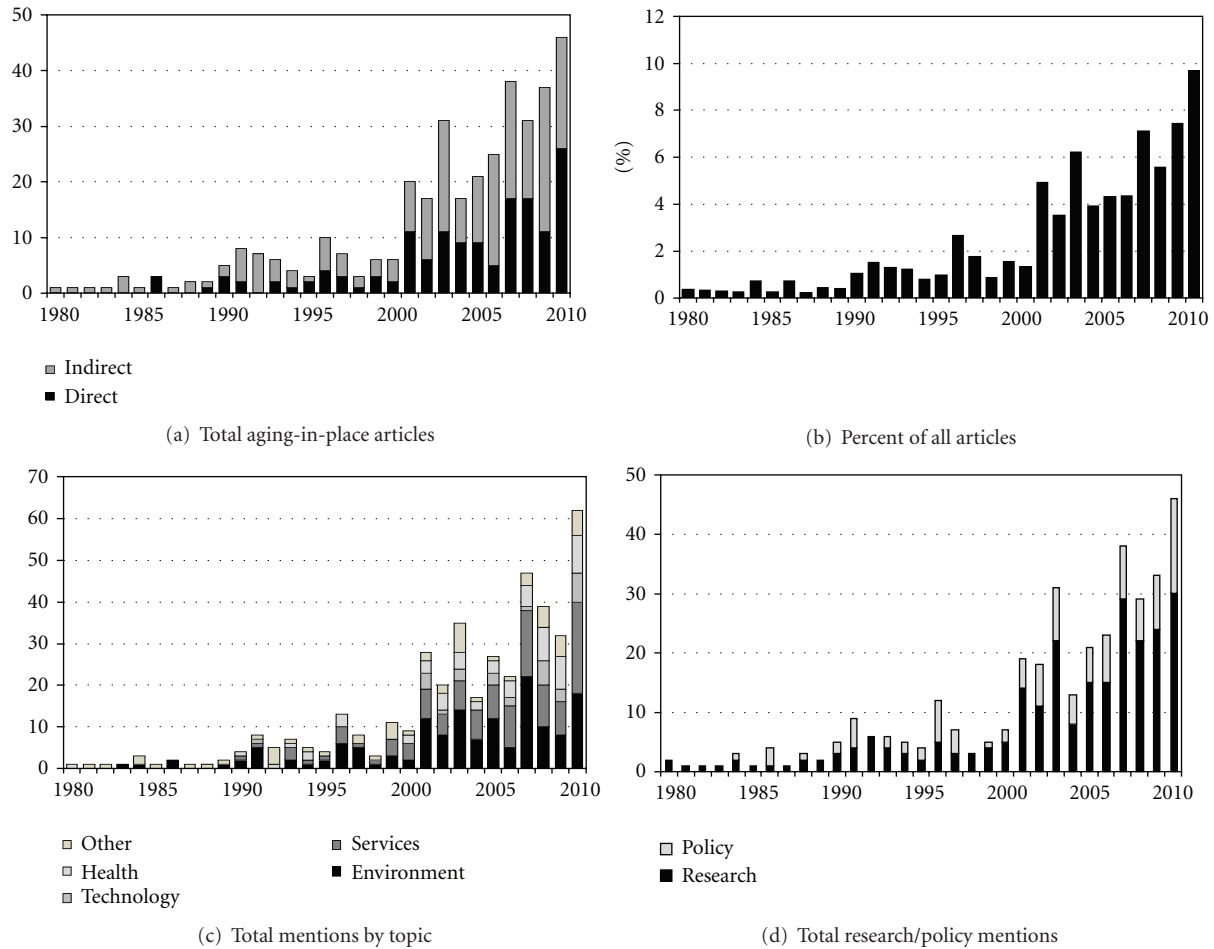


FIGURE 1: (a) Absolute number of aging-in-place articles (direct and indirect mention), 1980–2010; (b) proportion of aging-in-place articles relative to the total published articles, 1980–2010; (c) absolute number of categorical mentions among aging in place articles published, 1980–2010*; (d) total aging in place articles by research/policy designation. *Categorical mentions are not mutually exclusive (e.g., one manuscript may have multiple category mentions).

these differences, the concept of aging in place has established itself internationally, with studies documented in Sweden [25], China [26], the United Kingdom [27], Japan [28], New Zealand [29], Australia [30], Malaysia [31], and Taiwan [32].

Fourth, technology has become an increasingly important component to the literature on aging in place. The worker interactive networking project is an example of the growing number of studies that examine the influence of technology in supporting working-family caregivers of frail and memory-impaired older adults [33]. Other studies focus on the mobile and e-communications among older Japanese adults [28], telecare initiatives to address issues related to the potential negative experiences associated with aging in place (e.g., lack of informal support [27]), and pain management through videoconferencing [34].

Although a number of articles focus on the importance of aging in place [35], others highlight the potentially negative experiences (e.g., isolation and loneliness) associated with remaining in the same location [27]. Such ideas are echoed by LeRoy and colleagues [36] who cautioned that aging in place does not assure a high quality of life, since continuity

of place is not always accompanied by a continuity of roles, relationships, and lifestyles (often the case for adults with dementia). Further evidence for this is provided by reports that changes in the environment can be associated with positive outcomes [37], in which older adults relocate to enhance individual development, pursue personal interests, and overcome restrictive environments.

4. Discussion

This study documents the increasing attention given to aging in place in the gerontological research community over the past 30 years. Our findings indicate the growing variety of topics pertaining to aging in place, ranging from housing and environment to health and technology. The relevance of this topic, we believe, has increased over time, in part due to the acknowledged preference of older persons (and younger persons with disabilities) to maintain independence, and to the greater availability of noninstitutional care. In addition, concerns about the escalating costs of institutional long-term care on the part of policy makers have made a priority

of concerns by older persons and their families, regarding the desire to avoid relocation in order to receive needed assistance. As a result of this reprioritization, new grants have been initiated to foster aging in place efforts that are based on evidence-based research findings, under the auspices of the National Institute on Aging (NIA), the Administration on Aging (AoA), and other federal agencies.

Although we believe that our findings illuminate a real and important growth in the quantity and diversity of aging-in-place publications, we acknowledge some limitations of the current study. Namely, by including only academic manuscripts in the eleven designated gerontology journals, we excluded books, scholarly publications from other related journals (e.g., those specifically pertaining to housing, economics, and technology), and reports by organizations that have focused specific attention on this issue (e.g., AARP). Our selected search terms also limited the inclusion of some publications, because of different terminology used among countries and cultures. For instance, some Europeans often use the term “staying put,” while other articles have used “home independence” to encompass the concept of aging-in-place. The use of the selected search terms to study aging in place would represent a more conservative estimate of trends and may provide a selective perspective of the concept. The current study provides a general synopsis of the trends in aging in place literature from 1980 to 2010, but further studies that examine this body of work across a number of other categories are warranted (e.g., studies that are classified based on cross-sectional versus longitudinal methods, interventions, personality, and subjective/objective perceptions regarding aging in place). Despite these limitations, we believe our analyses illustrate the emergence and arrival of aging in place as a focal concept in the scholarly field of gerontology.

In conjunction with worldwide population aging and the greater likelihood of surviving to an age when individuals are likely to require some form of daily assistance to achieve independent living, we have documented the concurrent growth in attention paid by gerontologists who often influence policy decisions regarding strategies and barriers to aging at home. Unfortunately, as of 2011, many barriers remain for older adults seeking alternatives to institutional care. This includes limited funding for programs that provide home modifications, service delivery issues, consumer awareness and training issues, and poor communication among government agencies that address health, housing, and services for older adults and people with disabilities [38]. In addition, excess expenditures associated with aging in place may, at times, outweigh alternative options to age in other settings [39]. Conversely, the savings overall, associated with multiple noninstitutional alternatives, may not always accrue to any particular program that provides support for aging in place. Aging in place may also require much more involvement of relatives, friends, and unpaid community members than involvement of institutional settings.

As a result of these challenges, there is a continued need for research and policy development that can be applied to address these problems. Specifically, researchers should continue to explore how policies, services, environment, and

technology influence aging in place, as well as the degree to which aging in place research informs and influences policy and services. Perhaps the biggest question surrounding our results pertains to how trends in aging-in-place literature translate to the needs and services currently provided to older adults. Additional studies are warranted in order to address this important and pressing question. Although aging in place seems to have come of age over this 30-year time period, we expect that future trends will exhibit a greater diversity of aging-in-place topics and that this concept will continue its upward trajectory within gerontology publications.

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Research Article

Home and Community Environmental Features, Activity Performance, and Community Participation among Older Adults with Functional Limitations

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This paper describes relationships among home and community environmental features, activity performance in the home, and community participation potential to support aging in place. A subset of data on older adults with functional limitations ($N = 122$), sixty three (63) with mobility and 59 with other limitations, were utilized in this study from a larger project's subject pool. Results showed significant and positive correlations between environmental barriers, activity dependence and difficulty at home, and less community participation in the mobility limitation group. While kitchen and bathroom features were most limiting to home performance, bathtub or shower was the only home feature, and destination social environment was the only community feature, that explained community participation. Compared to environmental features, home performance explained much more community participation. Study results provide detailed information about environmental features as well as types of home activities that can be prioritized as interventions for aging in place.

1. Introduction

Changes in the person-environment relationship as well as the negative outcomes of shrinkage in “life space” (i.e., the extent of mobility of older adults as measured by the range of places in which a person engages in activities within a designated time frame) associated with aging, particularly among seniors with mobility limitations, have been long conceptualized and widely documented [1–3]. In fact, restricted life space has been recently linked to increased risk of Alzheimer's disease [4]. Older adults have been reported to spend 80 percent of their time in their primary residence [5] and have demonstrated an “environmental centralization” of behaviors (i.e., the tendency of using a few preferred places at home where necessary or desired items are located) to maintain control and competence over the living environment [2, 6]. With almost 9 out of 10 (86%) older Americans reporting that they want to spend the rest of their lives in the homes and communities [7] in which the majority of their daily activities take place [8], a robust life space is essential

for older adults to continue to engage and participate in as many home and community activities as independently and safely as possible.

While prior work has consistently linked supportive home and community settings to continued performance of home activities and participation in community roles, respectively, evidence suggests that community participation, which is dependent on maintaining a wide range of life spaces outside the home, may also be affected by one's level of dependence and difficulty in performance of daily activities in the home [9]. Further, activity dependence and difficulty may be differentially affected by the same environmental features [10]. To develop a more comprehensive understanding of the factors that affect performance or activities in the home and participation in the community among older adults with limitations in mobility, this paper will describe the relationships among (1) home environmental features and performance of routine activities in the home as measured by task dependence and difficulty, (2) home and community environmental features and opportunities

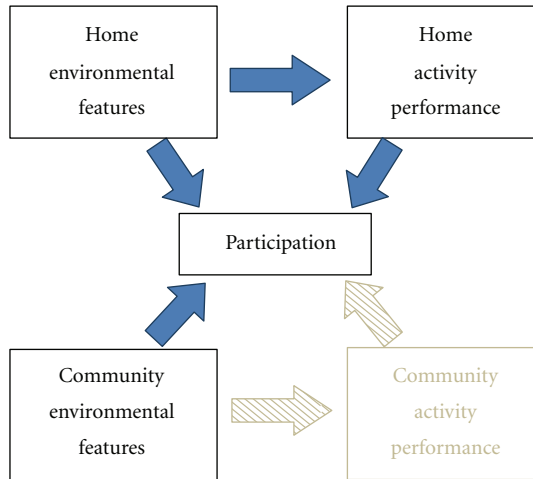


FIGURE 1: Based on the ICF, environmental press, and life space models, the conceptual framework for the study illustrates the relationship between home and community environmental features and home and community activity performance, respectively. In addition, activity as a prerequisite for participation suggests that home and community activity performance, in turn, influence participation in both settings although, as indicated by the dark filled arrows, this study only examined the relationships between community participation and (1) home and community environmental features and (2) home activity.

for community participation as measured by the frequency of travel to community life space destinations, such as restaurants, grocery stores, doctor's offices, and recreational areas, and (3) dependence and difficulty in home activities and opportunities for community participation (see Figure 1).

1.1. Underlying Models. The theoretical bases of this study are derived from models of person-environment interaction, including two ecological models, the international classification of functioning, disability, and health (ICF) [11] and the environmental press model [1] and the life space model [12, 13]. The ICF provides a model that defines performance and participation as the interaction between the context, including the physical environment, and an individual's functional ability. The ICF also describes the interactions between activity performance and participation. Based on these underlying principles, this study examined the association between environmental factors and performance at home and participation in the community as well as interactions between home performance and community participation.

The second ecological model, the environmental press model, has long played a major role in defining environmental contributions to activity and participation. Derived from the environmental press model, the environmental docility hypothesis suggests that the impact of demands is a function of an individual's ability. In other words, individuals with less ability will be impacted more by the same environmental demands than individuals with greater levels of ability. Based on the environmental docility hypothesis, this study

examined the effects of environmental features on activity performance and community participation outcomes of older adults with and without mobility limitations.

The life space questionnaire, as developed by Stalvey et al. [12], illustrates the movement trajectory of older adults in nine environmental zones from the bedroom, immediately outside the home (e.g., porch/patio), outside the home (e.g., yard or parking), immediate neighborhood, outside immediate neighborhood, outside the town, outside the county, outside the state, to outside the country. Due to the increased time spent inside home and decreased participation in the community among older adults [5], this paper used a simplified version of the life space concept that focuses on older adults' ability to move from inside their homes to life spaces in the community (including both immediate neighborhood and outside immediate neighborhood). As a result, use of community life space reflects the potential for community participation. This dichotomization from home to community spaces is critical as increasingly accessing community spaces provides and enhances opportunities for continued participation in societal roles [14].

1.2. Impact of Home and Community Environmental Factors on Activity and Participation. Most previous studies of environmental supports for aging in place have separately examined associations between either the home environment and activity performance or the community environments and participation. As a result, a comprehensive understanding of the interrelationships among home and community environments, performance, and participation is still lacking [15].

In *home settings*, unsupportive home features have been linked to greater difficulty and dependence in daily household activities [10, 16, 17]. In contrast, the provision of supportive environmental features, such as grab bars and home modifications, has been shown to enhance independence in activities, reduce caregiver burden, and decrease home care costs [18–20]. Most of these studies tend to associate the number of barriers/facilitators [20], a global score of environmental misfit [16, 17], or broad domains of home barriers/facilitators (e.g., overall bathroom barriers) [18, 19] to performance outcomes rather than linking specific home features (e.g., bathtub space or bathtub height) to specific performance outcomes (e.g., getting in and out of tub). As a result, these studies generally do not depict the differential impacts of specific home environmental features on explicit performance outcomes. One of the few exceptions [10] was a study that described correlations between home facilitators (i.e., home modifications) with both activity independence, and ease of performance in 15 home tasks by individuals with mobility impairments. However, none of the factors, home environmental features, activity independence or ease of performance were linked to community participation.

In *public settings*, physical environmental factors, such as mixed land uses, highly connected street networks, availability (e.g., number and types) of stores and services, pedestrian-friendly streets and sidewalks, neighborhood attractiveness, and transportation, were linked not only to engagement in activity (e.g., exercise or walking to community destinations) of older adults, but also to their propensity

to participate in society [21, 22]. Conversely, a study that examined the impact of specific environmental factors on activity and participation of seniors who used wheeled mobility aids reported that among the 50 factors examined, including 17 sidewalks, 17 crossings, 10 curb ramps, and 6 ramp characteristics, all 50 significantly prevented the 95 percentile of older wheelchair population from going out into the community, thus restricting opportunities for participation when those barriers were present [23]. Yet, other studies have found that the overall impact of the environment on participation was smaller than expected [24–27]. While mobility and balance (as opposed to other personal factors) explained 24% of participation in one study [24] and activity limitations explained much of community participation in another [25], in a third study, community environments, such as governmental and public services and physical environment and accessibility, only accounted for 6% of the variance in participation [26]. These data suggest that perhaps other factors, such as environmental factors in the home, may play a key role in community participation.

In contrast to studies that focused on community features alone, Haak et al. [15] reported that a *continuum of home to community features* was significantly correlated with participation. However, while the study examined the impact of mostly social environmental supports in the community, such as good medical care in the vicinity, living close to friends and relatives, cultural opportunities in the vicinity, and having good local transport, specific physical environmental factors were not included. Moreover, although physical barriers in the home environments were included, these were aggregated to a number of environmental barriers and magnitude of accessibility problems. As a result, the impact of specific features on participation could not be assessed.

To date, only one study has examined the interaction between home environmental factors and community participation. In a pre-post study prior to and after receiving home modifications for getting in and out of the house, moving around the house, and using the bathroom, Hammel et al. [9] examined older adults' ability to use a range of life spaces within and outside the home when they wanted and with whom they wanted. After receiving home modifications, participants not only reported an increased use of community life spaces, but they also used more distant life spaces. Most importantly, among all of the types of home modifications made, toilet and bathtub modifications, even more so than ramps and lifts for getting in and out of the house, demonstrated the largest effect on going out into the community.

2. Purpose

Recognizing the complex interactions among environments, home activity performance, and community participation and the potential impacts on the ability of older Georgians to successfully age in place, the Georgia Council on Aging, which serves in an advisory capacity on aging issues to the Governor and General Assembly of Georgia, supported a survey to identify and prioritize the environmental and

TABLE 1: Research questions.

		Dependent variables	
		Home activities	Community participation
Independent variables	<i>Home features</i>	RQ1	RQ2
	<i>Community features</i>		RQ2
	<i>Home activities</i>		RQ3

performance correlates of unmet home activity and community participation needs of Georgia's seniors. The goal of the survey was to develop a comprehensive understanding of home and community environmental barriers and facilitators that impact the activity and participation of Georgia's seniors to inform policy and prioritize service delivery needs for the State of Georgia. In addition, the data are useful in developing a more comprehensive understanding of community participation potential and life space restriction as a function of the interrelationships among home and community environmental features and home activity performance.

The data reported here described relationships between the home setting (i.e., environmental features and activity performance) and community participation potential of Georgia's seniors with mobility limitations compared to those without mobility limitations. Mobility limitation was selected as a subset of interest because this group is more likely to experience more environmental barriers and life space restriction than older adults with other limitations (i.e., hearing, vision, speech, and dexterity), but without mobility limitations. Specifically, the paper will address three key research questions by describing the associations among (1) home environmental features (i.e., barriers and facilitators) and activity performance in the home as measured by dependence and difficulty in home activities of seniors with mobility limitations compared to those with other limitations, (2) home and community environmental features and community participation potential as measured by usage of community life space (i.e., the frequency of going into community destinations, such as restaurants, grocery stores, doctor's offices, and recreational areas among older adults with mobility limitations compared those with other limitations) of seniors with mobility limitations compared to those with other limitations, and (3) home activity (i.e., dependence and difficulty) and community participation potential of seniors with mobility limitations compared to those with other limitations (see Table 1).

3. Methods

The study employed a cross-sectional survey design to explore the relationships among environmental features, dependence and difficulty in activity performance in the home, and life space usage in the community participation to understand the met and unmet activity and participation needs of older Georgians. A web-based survey hosted by Survey Gizmo was developed to solicit input from Georgia's

seniors. Survey Gizmo was chosen because it is compliant with Section 508 of the Rehabilitation Act and is generally the most accessible and usable online survey platform. In addition, it utilizes an encrypted connection to ensure confidentiality of data. To ensure inclusion of older adults who did not have access to an online platform, alternative paper and telephone formats were made available. This project was approved by the Georgia Tech Institutional Review Board (IRB).

3.1. Participants. A total of 239 individuals with and without functional limitations who were 60+, living in the State of Georgia and had resided in their current residence for at least one year, were recruited for the survey. Seven out of 179 online surveys and 6 out of 54 written surveys were eliminated due to large amounts of missing data, resulting in a total of 226 participants in the study.

Participants were asked to indicate whether they experienced one or more of five functional limitations, including vision, hearing, speaking, moving around, and hand manipulation. Among the total of 226 participants, 122 had at least one of the five functional limitations. The 63 respondents who answered “yes” to the question: “do you have difficulty with moving around?” were included in the mobility limitation (ML) subset reported in this paper. The 59 participants who responded with a “yes” to any of the other 4 limitations were included in the other limitation (OL) group. It should be noted that because participants could respond to more than one limitation, the OL group included 52 individuals who had vision, 60 who had hearing, 26 who had hand manipulation, and 4 who had speaking limitations.

3.2. Procedures. A convenience sampling technique was employed in order to reach the required sample of 200 participants to achieve a statistical power of 80. Subject recruitment took place from November, 2009 to September, 2010. Participants were recruited through a variety of methods, including subject registries maintained by the Center for Assistive Technology and Environmental Access at Georgia Tech, as well as through email invitations and posts at AAAs, AARP, NORCs, senior centers, and other senior-related organizations throughout Georgia. Both email invitations and posts were provided with a brief study description and researchers’ contact information so that potential subjects who were interested in the study could actively contact the researchers by phone or email. All subjects that expressed an interest in the study were given a more detailed study description and a written informed consent form. Those who consented to participate were given the choice of taking an on-line, written, or telephone survey. Those who chose an on-line method ($n = 179$) were emailed with the link to the on-line survey. Hardcopy, text versions of the survey ($n = 54$) were mailed out with a self-addressed stamped envelope. The telephone survey ($n = 6$) was scheduled with the participant at a time that was mutually agreeable. The survey took approximately 20 minutes online and 30–40 minutes in a written or telephone format.

3.3. Survey Instrument. The survey gathered self-perceive information on a variety of factors, including (1) activity performance, (2) community participation potential, (3) environmental barriers and facilitators, and (4) participant demographics. All survey questions were answered by participants without assistance from the researchers. Based on a comprehensive review of literature, the survey borrowed from and adapted questions from a number of existing instruments, including *comprehensive assessment and solution process for aging residents (CASPAR)* [28], *the healthy aging research network (HAN) environmental audit tool and protocol* [29], *the facilitators and barriers survey of environmental influences on participation among people with lower limb mobility impairments and limitations (FABS/M)* [30], and *the participation survey: mobility (PARTS/M)* [31].

Activity performance and environmental barriers/facilitators in the home were adapted from the CASPAR [28]. CASPAR was chosen because it associates demand-producing environmental attributes (which could be barriers or facilitators) with actual activity performance [28, 32]. In contrast, other existing home assessment instruments that compare environmental attributes to performance, such as the housing enabler [33], focus on environmental barriers and not assess actual performance. Rather, activity performance (e.g., cannot go up and down the ramp to get in and out of the house) is predicted from a comparison of environmental attributes that are expected to be barriers (e.g., ramp slope) to an individual with functional limitations that interact with those attributes (e.g., lower body motor limitation). This approach is useful in informing decisions about home modification needs when actual performance cannot be observed, such as prior to an individual’s discharge from a rehabilitation facility, but because it only predicts performance that may or may not actually occur, it may result in false positives as well as underestimating problems. As a result, these types of predictive assessments did not provide sufficient information to make decisions about environmental modification needs. CASPAR, in contrast, which associates environmental attributes against actual activity performance, results in information that could be used by the Georgia Council on Aging to determine actual environmental modification needs [34].

The CASPAR includes self-reported information on functional abilities, types of performance problems with person-environmental transactions, such as getting on and off toilet, and detailed measures of activity-relevant environmental attributes of the home, such as height and location of toilet. The sections of performance and environmental attributes were utilized and adapted for the current study. For example, in the environmental section, direct measurements of home attributes such as bathtub dimensions were omitted as provision of modification intervention was not the intent of this study. Instead, perceived impacts of environmental attributes on matching task performance were surveyed. That is, participants were asked to rate on a 5-point Likert scale from “limits a lot” to “helps a lot” to be consistent with the response system in the measure of community environment. In addition, to shorten the time required for survey administration, the number of home environmental

features in CASPAR was reduced from features in eight activity areas (i.e., getting in and out of the house, using interior stairs, moving around the house, using the bathroom, using the bedroom, using the kitchen, using the laundry, and controlling ambient conditions) to those in four activity areas that were considered to be the most crucial for daily home activities (i.e., getting into and around the home, using the bathroom, using the kitchen, and using the bedroom). Interrater reliability and criterion validity of CASPAR were moderate to high on the majority of items [28].

Measures of community environmental barriers/facilitators were adapted from the *healthy aging research network (HAN) environmental audit tool and protocol* [29] and the *facilitators and barriers survey (FABS/M)* of environmental influences on participation among people with lower limb mobility impairments and limitations [30]. The HAN environmental audit tool and protocol was designed for research purposes and developed through both qualitative interviews and quantitative reliability testing at multiple sites [29]. This tool was chosen because it covers both physical and social attributes in the community. The total number of attributes in the original tool was 55, and they were grouped by the study researchers into a final list of 7 community features (i.e., stores, streets, sidewalks, visual appeal, public transit, and destination physical and social support) with descriptions of the original attributes under each of the seven categories in order to reduce survey burden placed on the participants. In addition, because the HAN environmental audit tool used both ordinal and categorical data, it did not lend itself to the ordinal scoring system needed to measure the magnitude of environmental features as barriers or facilitators to performance [29]. As a result, the ordinal response options in the FABS/M were adopted to measure person-environmental transactions (i.e., impact of community features and attributes on corresponding community activities or behaviors). The response options utilized a 5-point Likert scale from “limits a lot” to “helps a lot.” The FABS/M is a widely used measurement on community environments with sound psychometric properties [30]; however, as the FABS/M was not originally developed for the older population, its survey questions could not fully capture barriers and facilitators encountered by older adults. Therefore, only the response system was utilized in our study.

Finally, the *participation survey: mobility (PARTS/M)* was used to develop measures of community participation potential [31]. The PARTS/M was developed based on the international classification of functioning, disability, and health (ICF) and had good internal consistency and stability [31]. The PARTS/M measures the frequency of traveling to various community settings (e.g., restaurants, bank, doctor, and grocery) as an indicator of the potential for participation. In other words, travel to community destinations is a prerequisite to participation in societal roles. The more frequently individuals traveled to community destinations, the greater the likelihood that they would participate in societal roles. Conversely, the less often they traveled to community destinations, the fewer opportunities they would have to participate in societal roles.

3.4. Independent Measures. Independent variables included both *environmental features* rated as either barriers or facilitators and *functional limitations*. *Environmental features* included 17 features (e.g., steps, toilets, kitchen appliances, and bedroom closets) in four areas of the home (i.e., circulation, bathroom, kitchen, and bedroom) and 7 features in the community (i.e., stores, streets, sidewalks, visual appeal, public transit, and destination physical and social support). The degree to which any environmental feature was perceived to be a barrier or facilitator was defined by the perceived level of support, on a 5-point Likert scale from 1 = “helps a lot” to 5 = “limits a lot,” that was afforded by any particular feature.

Functional limitations were divided into two groups: mobility limitation group (ML) as defined by difficulty moving around and other limitations group (OL), as defined by having difficulty with vision, hearing, speaking, and/or hand manipulation, were used as the other independent variable. Each of the limitations was measured dichotomously (i.e., with or without a specific functional limitation). Respondents could select more than one limitation if applicable.

3.5. Outcome Measures. Dependent outcome measures included *activity performance at home* and *participation potential in the community*. *Activity performance* was measured by activity independence/dependence as well as ease/difficulty. Activity independence/dependence was defined as needing personal assistance while performing an activity, regardless of the use of assistive technology. Activity dependence was reported by subjects on a 3-point Likert scale from 1 = “independent,” 2 = “dependent,” to 3 = “unable to perform the activity.” Activity ease/difficulty was defined as self-reported ease or difficulty in performing each activity in the usual way (i.e., with or without assistance of another person). Four levels of perceived difficulty from 1 = “no difficulty,” 2 = “somewhat difficult,” 3 = “very difficult,” to 4 = “unable to perform the activity” were assessed. Both activity independence and difficulty address routine performance, that is, actual performance rather capacity to perform. The activities queried in the survey were adapted from the CASPAR, including three *circulation* tasks (getting in and out of the house, going up and down interior stairs, and moving around inside the house), two tasks for using the *bathroom* (getting on and off a toilet, getting in and out of a bathtub or shower), three for using the *kitchen* (using kitchen appliances, getting items in and out of upper cabinets, and getting items in and out of lower cabinets), and the two for using the *bedroom* (getting on and off a bed and using the closet).

Participation potential [35], adopted from the PARTS/M, was defined as self-reported frequency of actual community participation. It was assessed by one question, “how often do you actually go into destinations (such as restaurants, banks, churches, and recreational areas) in your community?” on six levels of frequency from “daily,” “several times a week,” “several times a month,” “once a month,” “less than once a month,” and “do not participate in the community.”

3.6. Demographic Data. Demographic data were used to describe the study sample, including *age* (i.e., year born), *gender*, *ethnicity* (i.e., white/Caucasian, African American, Hispanic or Latino, Asian, Native American/Alaskan Native, Native Hawaiian/other Pacific Islander, and other), *education levels* (i.e., no high school, some high school, high school diploma/GED, associate degree, bachelor's degree, master's degree, and doctorate degree), *community types* (i.e., urban, suburban, and rural areas), *mobility aids* (i.e., cane, crutch, walker, manual wheelchair, power wheelchair, and scooter) and *sensory devices* (i.e., hearing aids and glasses).

3.7. Data Analysis. Data from the online survey ($n = 172$) were automatically entered into an online database. Data from the written ($n = 48$) and telephone survey ($n = 6$) were hand entered. All written and telephone survey data were double entered to ensure accuracy. Spearman rho correlations were conducted for all three research questions, that is, to associate (1) home environmental features to independence and to difficulty of home activities, (2) home and community environmental features to participation potential, and (3) independence and difficulty of home activities to participation potential. Since matched sets of activity and activity-related environmental features (e.g., getting on/off toilet and toilet space and toilet) were used in research question 1, stepwise regressions were only conducted for research questions 2 and 3. Four stepwise regressions were further conducted to individually identify which (1) home and (2) community environmental feature that explain community participation for research question 2, and (3) independence and (4) difficulty in which home activities explain community participation for research question 3. Cohen effect size conventions of small = 0.10, medium = 0.30, and large = 0.50 were used for both correlation and regression analyses [36]. Both moderate and large effect sizes are interpreted to be clinically significant. Descriptive comparisons of all independent and outcome variables between the mobility and other limitation groups were all conducted by Chi-square analyses. Due to an exploratory and descriptive nature of this paper, results were considered to be significant at $P < .05$. Because the analysis of this data employed multiple independent analyses, uncorrected significance tests are not appropriate for inferential interpretation. However, significance is reported here with uncorrected P values to be interpreted as an arbitrary criterion of effect size strength in deference to its widespread use in social science for exploratory analyses.

4. Results

4.1. Descriptive Analyses

4.1.1. Sample Demographics. A total of 122 participants met the criteria of having "functional limitations" and were included in this analysis. Among these, the sample was approximately equally divided between the ML ($n = 63$, 51.6%) and OL groups ($n = 59$, 48.4%). Overall, the ML was fairly high functioning. More than 4 out of 10 (41%) did

TABLE 2: Demographics.

	All ($N = 122$)	Mobility/other limitation ($n = 63$)/($n = 59$)
Age		
Mean (S.D.)	72.5 (8.50)	71.2 (8.30)/ 73.9 (8.58)
Gender		
Male	36%	27%/46%
Female	64%	73%/54%*
Ethnicity		
Caucasian	74%	73%/74%
African American	22%	21%/22%
Hispanic/Latino	1%	2%/2%
Native American	2%	0%/2%
Other	3%	5%/0%
Education		
No/some high school	12%	14%/9%
High school/GED	30%	35%/25%
Associate/bachelors	32%	30%/33%
Graduate degrees	26%	21%/33%
Community types		
Urban	20%	21%/19%
Suburban	51%	50%/51%
Rural	29%	29%/27%
Functional limitations		
Difficulty with seeing	43%	40%/46%
Difficulty with hearing	49%	35%/64%†
Difficulty with speaking	3%	5%/1%
Difficulty with moving around	48%	100%/0%
Difficulty with manipulation	21%	18%/8%*

* $P < .05$; † $P < .01$.

not use mobility aids, while an almost equivalent percentage (38%) used a cane. Only 18% used walkers, 8% used power wheelchairs, 3% used manual wheelchairs, and 2% each used crutches and scooters. Almost two-thirds (64%) of the OL group had a hearing limitation (see Table 2).

The mean age of all participants with functional limitations was 72.5 (S.D. = 8.50) with the ML group being 71.2 years of age and the OL group being slightly older at 73.9 years of age, although the difference was not significant. The majority of the respondents was female (64%), Caucasian (74%), and living in suburban (51%) areas (see Table 2). In addition, almost one-third (32%) had an associate or bachelor degree. There were no significant differences in race or residence between the ML and OL groups (73% and 74% Caucasian; 50% and 51% living in suburban areas, resp.) although there were significant differences ($P < .01$) in gender (73% female in the ML group versus 54% in the OL group).

4.1.2. Environmental Features as Barriers and Facilitators. Overall, only approximately one in five respondents perceived barriers in either the home ($n = 18$, 14.8%) or in the community ($n = 26$, 21.3%). The most common home barriers reported by the whole sample included kitchen cabinets (24.8%), bathtubs or showers (23.5%), bedroom closets (23.5%), and steps (19.2%). The most common community barriers were streets (28.0%), sidewalks (28.0%), and number and of stores (23.5%). Conversely, the bathroom sink was the feature perceived by the lowest percentage (8.4%) of the whole sample in the home, whereas social environments in community destinations were perceived by the lowest percentage of respondents (14.4%) as a barrier in the community.

Similar to the whole sample, both ML and OL groups perceived more barriers in the community than in the home. Although the ML group perceived more barriers in each of the settings with 29% perceiving community barriers to 18% in the OL group and 17% perceiving home barriers to 12% in the OL group, neither was statistically significant. The home and community barriers cited most often by the largest percentage of the ML and OL groups were also similar to the whole sample. However, all home and community features were perceived as barriers by higher percentages in the ML group than the OL group with the exception of public transportation, which had equal percentages in both groups. However, among these features, only steps ($P < .05$) and kitchen cabinets ($P < .05$) in the home and the physical environment in community destinations ($P < .01$) were significantly higher in the ML than the OL group (see Table 3).

4.1.3. Activity Performance: Dependence and Difficulty. Dependence in each of the ten home activities ranged from 4.3% to 33.6% for the overall sample, with the largest percentage of respondents (33.6%) being dependent in getting items in and out of upper cabinets in the kitchen and the smallest percentage of respondents being dependent in getting on and off a toilet (4.3%). A significantly higher percentage of the ML group reported being more dependent than the OL group in eight of the ten home activities ($P = .000-.038$). Moreover, the trend continued with a higher frequency of respondents in the ML group reporting greater dependence in the other two activities, moving around inside house and getting items in and out of a closet, although the differences between groups were not significant.

Compared to activity dependence, higher percentages of the overall study sample reported having difficulty with the 10 activities ranging from 13% to 53.0%. The largest percentage of respondents had difficulty going up and down stairs (53%), whereas the smallest percentage had difficulty getting on and off a bed (13%). Similar to activity dependence, higher percentages of the ML group reported having difficulty in all ten home activities, although in this case, all activities were significantly ($P = .000-.022$) more difficult in the ML than the OL group (see Table 4).

4.1.4. Community Participation Potential: Frequency of Use of Community Life Spaces. In general, older adults in the study

TABLE 3: Perceived home and community barriers by percentage of responses.

Features	Mobility/other limitation Barriers (%) ¹
Circulation	
Walkway	19.4/8.5
Steps	24.2/13.8*
Doorway	12.9/7.0
Home space	16.9/13.8
Pathways	15.0/6.8
Door	13.6/10.0
Bathroom	
Toilet space	11.3/7.1
Toilet	16.1/12.3
Tub/shower space	14.5/10.5
Tub/shower	22.6/19.0
Sink	11.3/5.3
Kitchen	
Space	16.1/16.9
Appliances	11.5/11.9
Cabinets	30.6/18.6*
Bedroom	
Space	12.9/8.5
Bed	17.7/12.1
Closet	29.5/17.2
Community	
Stores	27.9/19.0
Streets	29.0/27.1
Sidewalks	37.1/24.1
Visual appeal	16.7/13.6
Public transit	17.2/17.2
Dest. physical	34.9/13.5 [†]
Dest. social	27.1/11.1

¹ Percentage of responses on "limit some" and "limit a lot."

* $P < .05$; [†] $P < .01$.

sample were generally active. Almost three-quarters ($n = 88$, 72.5%) of the overall study sample went into community at least several times a week ($n = 48$, 39.7%) or everyday ($n = 40$, 32.8%). Despite the large number of participants who were active, more than one-quarter demonstrated restricted life space by traveling to community destinations less than weekly (18.1%, $n = 22$) or once a month or less (9.5%, $n = 12$).

When the ML and OL groups were compared, as expected, a lower percentage of the ML group participated in the community everyday (28.6%) compared to the OL group (37.7%), although the differences were not statistically significant. The differences in community participation between the ML and OL groups were most evident among the least active community participants, with a trend ($P = .054$) toward more participants in the ML group (14.3%) demonstrating life space restriction (i.e., going into community every month or less) than the OL group (3.8%).

TABLE 4: Comparisons of performance and participation between mobility and other limitation groups.

Performance	Mobility/other limitation	
	Dependence (%) ¹	Difficulty (%) ²
Circulation		
Getting in and out of the house	15.9/0.0 [†]	55.6/7.5 [‡]
Going up and down stairs	39.3/9.3 [†]	82.5/18.5 [‡]
Moving around inside house	9.5/1.9	28.6/3.7 [†]
Bathroom		
Getting on and off a toilet	7.9/0.0*	25.8/5.6*
Getting in and out of a bathtub or shower	14.3/0.0 [†]	48.3/7.4 [‡]
Kitchen		
Using kitchen appliances	17.5/1.9*	33.9/7.4 [†]
Getting items in and out of upper cabinets	51.6/13.0 [‡]	64.5/32.1 [†]
Getting items in and out of lower drawers	27.4/1.9 [†]	54.8/7.4 [‡]
Bedroom		
Getting on and off a bed	9.7/0.0*	21.3/3.7*
Getting items in and out of a closet	6.1/3.7	24.6/5.7*
Participation		
	Frequency	Monthly ³
	<i>P</i> value	<i>P</i> value
Community		
Going into your community	N.S.	.054

¹Percentage of responses on “dependent” and “unable to perform.”

²Percentage of responses on “somewhat difficult,” “very difficulty,” and “unable to perform.”

³Going into community \leq or $>$ once per month.

* $P < .05$; [†] $P < .01$; [‡] $P < .001$.

4.2. Correlational Analyses

RQ1: What Is the Relationship between Home Environmental Features and Activity Performance in the Home? While almost none of the home features were significantly correlated with activity performance in the OL group, over half of the home barriers were significantly correlated with either activity dependence or difficulty in the ML group. More than three-quarters (76.6%) of the 17 home barriers were significantly correlated with activity difficulty, while 58.8% ($n = 10$) were significantly correlated with dependence.

Among the features in the four home spaces included in the study, all features in the kitchen, including kitchen space, appliances, and cabinets, positively ($r = .268-.627$) and significantly ($P < .001-.05$) correlated with both difficulty and dependence in performing the corresponding activities (i.e., using kitchen appliances, and getting items in/out of upper cabinets, getting items in/out of lower drawers). Two of the circulation features, steps and going up and down stairs, were significantly correlated with both the dependence and difficulty in going up and down stairs and moving around the house, respectively. Steps were positively and significantly correlated to dependence ($r = .520$; $P < .001$), and difficulty ($r = .303$; $P < .05$) in going up and down stairs, whereas home space barriers were positively and significantly correlated with dependence ($r = .377$, $P < .01$) and difficulty ($r = .364$, $P < .01$) in moving around the house. The other four circulation features were correlated with either

dependence (i.e., walkway and doorway) or difficulty (i.e., pathway and door) with r values ranging from $r = .276-.434$ and significance ranging from $P < .001$ to $P < .05$. In the bathroom, toilet features barriers were significantly correlated with both dependence ($r = .327$; $P < .01$) and difficulty ($r = .268$; $P < .05$) in getting on and off toilet; however, tub/shower features were only significantly correlated ($r = .257$; $P < .05$) with difficulty in getting in and out of bathtub/shower. Interestingly, neither space at the toilet nor at the tub/shower was significantly correlated with dependence or difficulty in getting on or off the toilet or in and out of the shower. Finally, in the bedroom, closet features were significantly ($r = .503$; $P < .001$) correlated with both dependence and difficulty in getting items in and out of a bedroom closet. The other two bedroom features, bedroom space ($r = .393$, $P < .01$) and bed ($r = .468$, $P < .001$), were significantly correlated with activity difficulty (see Table 5).

In the OL group, only three home features, kitchen cabinets, bed, and steps, were significantly correlated with activity performance at home. Two features, kitchen cabinets and bed, were positively correlated with difficulty in getting items in and out of lower drawers ($r = .292$; $P < .05$) and difficulty getting out of bed ($r = .316$; $P < .05$), respectively. In contrast, two home features, kitchen cabinets and steps, were negatively correlated with activity. Kitchen cabinets were significantly correlated ($r = -.342$; $P < .05$) with getting items in and out of upper cabinets, whereas

TABLE 5: Correlations between environmental features and (1) activity independence-dependence and (2) activity ease-difficulty.

Features	Mobility limitation	
	Independence-dependence	Ease-difficulty
Circulation		
	Getting in/out of the house	Getting in/out of the house
Walkway	.254*	N.S.
Steps	N.S.	N.S.
	Going up/down stairs	Going up/down stairs
Steps	.520 [‡]	.303*
	Moving around the house	Moving around the house
Doorway	.434 [‡]	N.S.
Home space	.377 [†]	.364 [†]
Pathways	N.S.	.276*
Door	N.S.	.297*
Bathroom		
	Getting on/off toilet	Getting on/off toilet
Toilet space	N.S.	N.S.
Toilet	.327 [†]	.268*
	Getting in/out bathtub	Getting in/out bathtub
Tub/shower space	N.S.	N.S.
Tub/shower	N.S.	.257*
Kitchen		
	Using kitchen appliances	Using kitchen appliances
Space	.461 [‡]	.391 [†]
Appliances	.467 [‡]	.443 [‡]
	Getting items in/out of upper cabinets	Getting items in/out of upper cabinets
Cabinets	.268*	.269*
	Getting items in/out of lower drawers	Getting items in/out of lower drawers
Cabinets	.464 [‡]	.627 [‡]
Bedroom		
	Getting on/off a bed	Getting on/off a bed
Space	N.S.	.468 [‡]
Bed	N.S.	.393 [†]
	Getting items in/out of a closet	Getting items in/out of a closet
Closet	.503 [‡]	.570 [‡]

* $P < .05$; [†] $P < .01$; [‡] $P < .001$.

steps were significantly correlated ($r = -.355$; $P < .05$) with independence in going up and down stairs.

RQ2: What Is the Relationship between Home and Community Environmental Features and Potential for Community Participation? Whereas community environmental features were significantly correlated to frequency of travel to community destinations in the ML group, they were not significantly correlated in the OL group. Although no environmental features in the home were significantly correlated with frequency of travel to community destinations in either the ML or OL groups, among the 7 community features, three,

including streets ($r = .294$; $P < .05$), sidewalks ($r = .283$; $P < .05$), and social environments of community destinations ($r = .346$; $P < .01$), were significantly correlated with frequency of going into community in the ML group.

Stepwise regressions were undertaken to further identify home and community features that explained travel frequency among the ML group. Results indicate that bathtub/shower was the only home feature that explains any significant amount, although slightly less than 6% (adjusted $r^2 = .055$; $P < .05$) of travel frequency. In the community, social environments at a destination was the only feature that accounts for a significant amount of variance (adjusted $r^2 = .130$; $P < .01$).

However, when frequency of travel to community destinations is dichotomized into frequent travelers (i.e., “more than once a month”) and infrequent travelers (“once a month and less”), frequency was significantly correlated with the majority of both home (64.7%, $n = 11$) and community (71.4%, $n = 5$) features in the ML group. Among home features, kitchen and bathroom features had the highest percentage of features that were significantly correlated with infrequency of travel to community destinations in the ML group, including four out of five (80.0%) bathroom features ($r = .289-.401$; $P < .01$ to $P < .05$) and all three (100.0%) kitchen features ($r = .252-.301$, $P < .05$). Among community features, stores, sidewalks, visual appeal, physical environments, and social environments were significantly correlated ($r = .268-.431$, $P < .001$ to $P < .05$) with infrequent travel in the ML group (see Table 6). In contrast, no home or community features were significantly correlated with dichotomized frequency of travel in the OL group.

In addition to correlations between environmental features and dichotomized participation, odds ratios were calculated for dichotomized environmental features (i.e., barriers/facilitators) and dichotomized participation (i.e., frequent/infrequent travel). In the home setting, all bathroom features, with the exception of bathroom sinks, had significant odds ratio results (i.e., the upper and lower CI95% did not overlap 1.00) in the ML group, while there were no significant results in the OL group. When toilet space, toilet, tub/shower space, and tub/shower were perceived as barriers, the odds of infrequent travel were 46.7, 25.0, 29.0, and 8.0 times higher, respectively, compared to when they were perceived as facilitators. Among community features, the odds of infrequent community travel were 17.8 times higher in the ML group when sidewalks were perceived as barriers and 21.3 times higher when social environments at the destination were perceived as barriers. Similarly, there were no significant odds ratios in the OL group in community settings.

RQ3: What Is the Relationship between Activity Performance in the Home and Community Participation Potential? As in other analyses, significant correlations were only found in the ML group. Again, in the ML group, there were a greater number of significant correlations between frequency of travel to community destinations and both kitchen and bathroom activities than circulation activities. There were no significant correlations between bedroom activities and frequency of travel to community destinations (see Table 7).

Comparing kitchen and bathroom activities, dependence of all kitchen activities and difficulty in all bathroom activities were positively correlated with less community participation. In the kitchen, dependence in using kitchen appliances, getting items in and out of upper cabinets and of lower drawers were significantly correlated with less community participation ($r = .272-.417$; $P < .01$ to $P < .05$). Among these three activities, getting items in and out of upper cabinets showed the strongest correlation ($r = .417$). In the bathroom, difficulty in getting on and off a toilet and getting in and out of a bathtub/shower were significantly correlated with less frequent travel to

TABLE 6: Correlations between environmental features and community participation and odds ratio results.

Features	Mobility limitation	
	Going into community \leq or $>$ once per month	
	r	OR
Circulation		
Walkway	.314*	N.S.
Steps	N.S.	N.S.
Doorway	N.S.	N.S.
Home space	.284*	N.S.
Pathways	N.S.	N.S.
Door	N.S.	N.S.
Bathroom		
Toilet space	.402 [†]	46.7
Toilet	.357 [†]	25.0
Tub/shower space	.376 [†]	29.0
Tub/shower	.289*	8.0
Sink	N.S.	N.S.
Kitchen		
Space	.301*	N.S.
Appliances	.278*	N.S.
Cabinets	.252*	N.S.
Bedroom		
Space	.355 [†]	N.S.
Bed	.254*	N.S.
Closet	N.S.	N.S.
Community		
Stores	.286*	N.S.
Streets	N.S.	N.S.
Sidewalks	.268*	17.8
Visual appeal	.297*	N.S.
Public transit	N.S.	N.S.
Dest. physical	.276*	N.S.
Dest. social	.431 [‡]	21.3

* $P < .05$; [†] $P < .01$; [‡] $P < .001$ (Spearman's rho).

community destinations ($r = .259$ and $.438$, $P < .05$ and $P < .001$, resp.). In circulation-related activities, both dependence in getting in and out of the house and going up and down stairs, as well as difficulty in getting in and out of the house, is significantly correlated ($r = .406-.463$; $P < .001$ to $P < .01$) with less frequent travel to community destinations.

To identify the home activities that account for the largest variance in frequency of travel to community destinations, two stepwise regressions were undertaken. Activity dependence and difficulty were entered separately. For activity dependence, getting items in and out of upper cabinets and getting in and out of house explained approximately one-fourth (adjusted $r^2 = .246$; $P < .001$) of the variance in travel frequency. For activity difficulty, getting in and out of a bathtub/shower is the only significant activity in the model,

TABLE 7: Correlations between activity performance at home and community participation.

Home activities	Mobility disability	
	(In)Dependence participation	Ease/Difficulty participation
Circulation		
Getting in and out of the house	.406 [†]	.463 [‡]
Going up and down stairs	.421 [†]	N.S.
Moving around inside house	N.S.	N.S.
Bathroom		
Getting on and off a toilet	N.S.	.259*
Getting in and out of a bathtub or shower	.314*	.438 [‡]
Kitchen		
Using kitchen appliances	.289*	.292*
Getting items in and out of upper cabinets	.417 [†]	.320*
Getting items in and out of lower drawers	.272*	N.S.
Bedroom		
Getting on and off a bed	N.S.	N.S.
Getting items in and out of a closet	N.S.	N.S.

* $P < .05$; [†] $P < .01$; [‡] $P < .001$.

accounting for almost one-third of frequency of going into community (adjusted $r^2 = .306$; $P < .001$).

5. Discussion

This study described relationships among home and community environmental features, dependence and difficulty in activity performance at home, and frequency of travel to community life space as an indicator of participation potential. Specifically, the study demonstrated that home environmental features were not only significantly associated with activity difficulty and dependence in the home, but also with less restriction in life space. In fact, the latter was positively related to home features and home performance as well as community environmental features. These results clearly demonstrated our primary hypothesis that remotely located home environmental features and activity performance can impact community participation.

As expected, correlations were only significant among the ML group. However, this group also had lower performance and participation outcomes, which supports findings by Anaby and colleagues [24] that mobility and balance, more so than any other limitations, account for the largest variance in performance and participation. The lower performance and participation outcomes as well as the stronger link between environment, performance, and participation not only indicate the higher vulnerability in people with mobility limitations to age in place, but also postulate that both performance and environmental intervention are a potentially important strategies to facilitate aging in place.

RQ1: Home Features and Activity Performance at Home. Previous studies have identified top barriers to activity performance at home as well as environmental features to reduce dependence and difficulty [10, 16–20]. This study not only provides further evidence that home features impact

difficulty and dependence among mobility impaired seniors, but also suggests that features can be either barriers or facilitators. Kitchen features presented the primary barriers to both dependence and activity at home. This is not surprising as research and practice suggest that kitchen features are low-priority modifications as they are expensive, and kitchen activities are perceived to be easily substituted or skipped without impacting daily functions greatly, particularly in comparison to more critical bathroom and entry/exit modifications. As a result, the data suggest that many of the participants had modification needs in the kitchen. Surprisingly, bathroom features (i.e., tubs, showers, and toilets), rather than space, were significantly correlated to activity performance, which perhaps reflects the vast majority (almost 90%) of the sample that was ambulatory. Since maneuvering space is a factor that primarily affects wheelchair users, the results may be different if the sample had a larger number of wheelchair users.

RQ2: Environmental Features and Community Participation Potential. Not surprisingly, community features were more strongly related with overall community travel than home features. Nonetheless, like their impact on home activity, the majority of bathroom and kitchen features were also significantly related to infrequent community travel. This was particularly true of bathtub or shower design (e.g., size of bathtub or shower, height of bathtub edge, or shower threshold) which accounted for a significant amount of the variance in travel frequency. Moreover, when the four toilet and bathing features, toilet space, toilet design, tub/shower space, and tub/shower design, were perceived as barriers, respondents were 8 to 46.7 times more likely to travel into the community only once a month or less.

These findings are consistent with a previous study [9], which reported large effect sizes of toilet and bathing interventions on community travel. One possible explanation is

the toilet and bathtub create such significant barriers such that the amount of time and energy required to toilet and bathe limits the amount of time that can be spent in the community. Alternatively, people may feel that the barriers limit their personal hygiene activities and are therefore less willing to travel into the community.

In addition to home environmental features, the social environment at community destinations, such as staff's willingness to offer assistance in a restaurant, not only showed the strongest correlation among all community features, but also it was the only community feature that attained significance in explaining the variance in community travel frequency. Social environment at community destinations also shows stronger odds ratio to community participation between the only two significant community features. However, together bathtub/shower and destination social environments only explained little (5.5% to 13%) of community travel. Such findings are consistent with previous literature, in which community accessibility only accounted for 6% of the variances in participation [26]. Our finding of positive correlations between home barriers and less community participation was also consistent with results from Haak and colleagues [15] that significant correlations between the number of home barriers and community participation were reported. Despite this, our findings identified specific home and community features that were significantly correlated to participation, which suggests a potential direction for further research, if not environmental intervention.

RQ3: Activity Performance at Home and Community Participation Potential. Similar to home barriers, performance challenges at home were positively correlated to less community participation, especially in kitchen, bathroom, and circulation-related activities. Dependence in getting items in and out of upper kitchen cabinets and getting in and out of the house explained 24.6% of community travel patterns. The former was significantly related to barriers of upper cabinets in the kitchen, including height of cabinets and handle styles, and it entails the likelihood of a positive association between decreased mobility/balance function and increased difficulty in community participation. The latter was significantly related to barriers of walkways such as physical condition or material of the street, driveway, and lighting, and it points out the importance of achieving independence in getting in and out of the house because assistance cannot be always handy.

In addition to dependence at home, difficulty in getting in and out of bathtub or shower also explained 30.5% of community travel. One possible explanation is the increased time and energy spent in the bathroom that reduces the time and energy available for going out into the community. Difficulty in getting in and out of the tub or shower was significantly correlated to barriers in the tub or shower, which also corresponds to predictors of home barriers to community participation. While previous research has shown the strong contribution of activity limitation to participation [25], our findings further described the type of home activity as well as the kind of performance indicator related to community participation.

This study provides the first step to comprehensively understand the relationships between home and community environments, home performance, and community participation as they impact aging in place. However, the study was limited by a number of factors including a small sample of convenience, which resulted in small effect sizes on many correlation results, and, ultimately limited generalizability of the data. The sample itself was an artifact of the time frame and funding allocated to the project, which limited the sample size and the data collection options. Although many of the correlations in the results had small to medium effect sizes, the prediction of difficulty in using the tub/shower to community participation achieved a moderate to large effect size. Both moderate and large effect sizes are interpreted to be clinically significant [36]. Future studies should increase the sample size to enhance the effect size. Further studies should also include and control for covariates, such as functional level and living situation, in the examination of the environment and performance predictors for aging in place. However, despite the limitations, to the authors' knowledge, this is one of the first studies that provides a more robust and comprehensive understanding of the impact of home and community environmental factors on home activity performance as well as community participation of older adults. Such an understanding of the impact of home and community features as well as itemized home activities provides a more viable "recipe" for intervention to facilitate aging in place.

6. Implications

This study has several implications for policy makers and practitioners. First, individuals with mobility limitations were found to be more vulnerable to the environment than those with other types of limitations, which suggests that environmental interventions for aging in place should first target at older adults who have difficulty moving around as they are the most environmentally vulnerable. Most importantly, environmental modifications should be conceived as a continuum of interventions from home to community in order to support both the activities and community participation that are necessary for successfully aging in place. In doing so, understanding the effects of interventions across settings is an important tool in identifying and prioritizing environmental modification needs for making decisions in policy and practice.

In addition, findings from this study suggest that contrary to current policy and practice that focus on independence as the primary intervention goal, both dependence and difficulty in activity performance predicted much of community participation. In fact, more home barriers were correlated with difficulty than dependence at home in our sample. Many older adults may not ask for assistance at the onset of functional declinations but may have already started experiencing difficulty in basic home activities. This may not only reduce the time they have available for community participation and other meaningful activities but may also pose potential safety hazards. Therefore, reducing activity difficulty should be a directed intervention goal in order to detect early unmet needs for aging in place.

Finally, our results provide more detailed information about environmental features that can be prioritized as interventions for aging in place. Targeted home features to enhance both home performance and community included accessible bathtubs or shower, walkways, and kitchen features. In the community, it is important to pay more attention to the social environment in the destinations to promote participation. Ultimately, a good physical environment will never overcome a bad social environment, but a good social environment can overcome a bad physical environment. Possible interventions could include disability awareness training for all community members and community social support system and network, to enable older adults to participate in the community and successfully age in place.

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Research Article

Dementia Home Care Resources: How Are We Managing?

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With the number of people living with dementia expected to more than double within the next 25 years, the demand for dementia home care services will increase. In this critical ethnographic study, we drew upon interview and participant data with persons with dementia, family caregivers, in-home providers, and case managers in nine dementia care networks to examine the management of dementia home care resources. Three interrelated, dialectical themes were identified: (1) *finite formal care-inexhaustible familial care*, (2) *accessible resources rhetoric-Inaccessible resources reality*, and (3) *diminishing care resources-increasing care needs*. The development of policies and practices that provide *available*, *accessible*, and *appropriate* resources, ensuring *equitable*, not necessarily equal, distribution of dementia care resources is required if we are to meet the goal of aging in place now and in the future.

1. Introduction

The number of people living with Alzheimer's disease or related dementia (ADRD) is expected to more than double within the next 25 years, affecting over 1.1 million Canadians and their families [1, 2]. Half of those with dementia live at home [3], and this proportion is increasing [4], especially amongst women [5]. Furthermore, families and friends are often the ones called upon to provide between 70%–90% of care [6] with adult children providing more care for their mothers than for their fathers. Clearly, the increasing number of people with ADRD will inevitably affect both formal and familial care for persons with ADRD who, on average, require care for approximately 8.5 years [7].

The challenges of providing home care have been well documented. Lack of support for family caregivers [8–11], lack of recognition and poor working conditions of home support workers [12, 13], early hospital-to-home discharge policy [14], and poor system coordination [15] are examples of the challenges faced by persons living with dementia

and their familial and formal caregivers. Furthermore, limited resources to implement and sustain a home care infrastructure [16] and a shift of chronic care to community settings without the corresponding transfer of funds [17] compound the difficulties encountered. Although provincial government-funded home care agencies in Canada are mandated to assess and coordinate the health care needs of community-dwelling older adults with dementia, there is evidence that increasing caseloads among direct care providers [13] and case managers [18] have negatively impacted the quality of home care.

In Ontario, 67% of formal home care has been provided by personal support workers and 27% by nurses, many of whom assume the role of case manager [19]. Case management, including assessment of client care needs and service allocation, coordination, monitoring, and evaluation based on assessed need, is a major strategy for home care management. Case management of home-based dementia care generally falls within one of three major models: (1) a

brokerage model wherein case managers are charged with the responsibility of assessing the needs of clients, and based on these assessments, “decide, access, coordinate, monitor, and control amounts of timeframes of resources and services” [20, page 120]; (2) integrated service allocation and care managed by *teams of professional providers* who work directly with clients, sharing the responsibility and accountability for the management of both care and service allocation; (3) consumer-managed care, directed by the clients themselves, where clients select different mixes of services to achieve what they value [21]. All three models, however, typically rely on a range of human resources, which include family, friends, and neighbours (informal network), as well as professional and paraprofessional services (formal network).

With the impending increase in the population of older persons in Canada, the availability of these human health resources to meet the growing demand for home care services is of rising concern to health care planners, policymakers, and other stakeholders [22, 23]. Furthermore, the need to both gain access to formal services and to sustain high levels of care may well exceed families’ resources [24]. Consequently, as demands for home care escalate and the number of people living with dementia in the community increase, investigation into the management of dementia home care resources is critical if the goal of aging in place is to be realized.

This article focuses on home-based dementia care from the perspective of persons with dementia, their family members, and home care providers, situating these experiences within a sociocultural context. In particular, we examined the relational experiences of clients, family caregivers, and providers involved in dementia home care, and the contextual factors that influence the formation and negotiation of those relationships, with the ultimate aim of identifying the necessary policy and practice changes to improve dementia home care. Four integral relational care processes emerged from our findings: *reifying care norms*, *managing care resources*, *making care decisions*, and *evaluating care practice*. This paper focuses on one relational care process, *managing care resources*.

2. Literature Review

Previous research on home support has identified that one of the challenges for home care workers is forming and maintaining relationships with clients and their family caregivers [25, 26]. Although the formal sector relies heavily on familial caregivers (families and friends) to provide the vast majority of care to persons with dementia, there has been little investigation of the relationship between the formal and informal home care networks. The few studies that have been conducted on home care [9, 27–30] have revealed an “uneasy alliance” and power struggles between the family caregivers and providers. Analysis of focus groups of 46 American home care clinicians revealed five inherent conflicts affecting family caregiver-clinician interactions: unrecognized family involvement; competing priorities and little time; lack of appropriate services to meet family needs; dual obligation of patient advocate and service gatekeeper;

the reservation of social work services for difficult cases [9]. While collaboration is typically sought by both formal and familial caregivers, these individuals are situated in an emotionally charged “intermediate” domain, a contested area between the public world of paid care and the private world of family care [10, 11]. Thus, alliances between formal and familial care providers in home care are often formed under the guise of partnerships.

Those studies that have explored home-based dementia care services have focused on the relationships between family caregivers and home care providers [31–33], family caregivers’ expectations of providers [15], the use and satisfaction with home-based service for persons with dementia [34], and the relationship between formal and informal care systems [35]. In a mixed-method study, Forbes et al. [34] found that 39 family caregivers of persons with dementia identified availability and accessibility issues in seeking and using formal home care and community services in three provinces in Canada. The qualitative component of this study revealed challenges of service availability (e.g., lack of community based dementia care) and accessibility (e.g., lack of system coordination), however, our understanding into how the two care systems might “work together” in providing accessible and appropriate resources remains unclear.

Although the relationship between the informal and formal care systems has been studied in a variety of settings, including home care [36–38], there are inconsistent findings about whether they substitute or complement one another. For instance, Zhu et al. [35] found that the utilization of formal home care and informal care was not influenced by the use of the other, and yet, there is empirical evidence that the two care systems are complementary [36, 37]. The theoretical basis and empirical support for both these approaches to understanding the link between formal and informal care systems are problematic [38]. First, the “partner relationship” between paid and unpaid care providers is espoused primarily by formal service providers and administrators as a way to limit financial expenditures of formal home services. In other words, the complementarity of the two systems is less compatible than is often assumed. Second, the analysis that guides most empirical studies on the relationship between formal and informal care systems is premised on the gendered assumption that the two are distinct entities, with family care rarely depicted as “care work”. This view not only simplifies the relationship between formal and informal caregiving, but it also fails to capture the specific commonalities and discerning differences between them. Thus, the differences between the two care systems with respect to power, status, authority, and resources are rarely considered in these studies. One exception, however, was Ward-Griffin and Marshall [38] who found home care nurses and family caregivers of older chronically ill elders living in Canada engaged in a bidirectional labour process of “work transfer”, one that depended on the “free” labour of family caregivers. Although this particular study sheds light on the complexity and interconnectedness of formal-informal care and points to the need to conceptualize eldercare as work, regardless of who does it, it did not focus on dementia home care.

There is also a need to examine the sociopolitical context of dementia home care because it permeates care systems at all levels [39]. For instance, a family member's "decision" to provide care to persons with dementia and to use formal care services depends on a number of sociocultural factors, such as the availability and cost of these services [40]. Family caregivers of persons with dementia also face a number of challenges in obtaining adequate, appropriate, consistent, flexible, and sufficient home care services [33, 34]. Since the conceptualization and availability of both informal and formal resources are profoundly shaped by the beliefs, values, practices, and policies within the current home care context, further investigation is warranted.

In summary, there is limited research that examines the sociopolitical context of dementia home care. Given the increasing use of home care services, the projected decreasing availability of family caregivers and the increasing number of persons with dementia health care practitioners and policy makers would benefit from an increased understanding of the perceptions and experiences of persons with dementia, and their familial and formal care providers with regards to the management of home care resources.

3. Study Design

The purpose of this critical ethnography was to develop a better understanding of home-based dementia care within a sociocultural context, shedding light in particular on those sociocultural, taken-for-granted values, beliefs, and practices embedded in the dementia home care culture.

3.1. Setting. As in other Canadian provinces, home care in Ontario entails the delivery of a wide range of health services to people of all ages who may be recovering from an illness, disabled or terminally ill. The central agency through which families access community care begins to manage a "case" by triaging it into one of five care domains: acute care, rehabilitation, maintenance, long stay supportive, and end-of-life care; seniors with dementia are usually classified into maintenance or long-stay supportive categories. Thereafter, care planning begins with a standardized assessment of the person with dementia's functional independence, couched within a goal-oriented model of client empowerment that aims to match services with assessments and with client preferences and strengths. As such, individuals receiving home care may be provided with medical, nursing, social, or therapeutic treatment or with assistance with essential activities of daily living. The fiscal constraints that characterize the province of Ontario's health care, however, preclude the provision of assistance with instrumental activities, such as housework, shopping, or meal preparation.

3.2. Recruitment. Case managers of the local Community Care Access Centre (CCAC) and other community collaborators served as key informants assisting with the identification and recruitment of potential procedures. All persons involved in the "caregiving network" of nine persons with dementia were required for this study. To be included

in the study, clients with Alzheimer's disease or related dementia had to speak and understand English, be at least 60 years of age or older, and have at least one family member or close friend providing regular care (minimum of 4 hours of direct or indirect care per week). Once the client and family caregiver(s) agreed to participate in the study, the home care worker(s) assigned to their care, for a minimum of three home visits, was invited to participate in the study by a member of the research team.

3.3. Sample. The total sample was comprised of nine networks, which included nine older adults with dementia, 25 family caregivers, 10 formal healthcare providers, and 7 CCAC case managers. The nine persons with dementia (PWD), four of whom were male, ranged in age from 75 to 91 (average 83.7 years). All but one were married, one was a widow, three had postsecondary education, one had only primary education, and the remaining PWD had secondary education. Standardized Mini Mental State Exam (SMMSE) scores ranged from 10/30 to 26/30, averaging 15.8 ($n = 5$; four scores were not obtained due to participants' relocation, refusal, or confusion). All PWD and their families were white and of Anglo-Saxon descent. Of the 25 family members who were spouses ($n = 5$, 3 of whom were male), the average age was 78.8 years. Among the adult children ($n = 20$, 15 of whom were female), the average age was 50.1 years. All but three adult children worked full time.

All nine networks were receiving formal home care support from personal support workers (PSWs). At least one PSW was recruited for each network (except network 9); for networks 3 and 8, two PSWs were recruited. In total, ten PSWs were recruited, two of whom were male. The average age of the PSWs was 52.8 years. Four worked full time, the others worked part time or on a casual basis. All seven home care case managers were female and of Anglo-Saxon descent. Their ages ranged from 45 to 57 (average: 50.9) years, and they had worked between 4 and 20 (average: 9.4) years as a case manager. Four of the managers coordinated caseloads that were primarily urban (i.e., within a large city in southern Ontario); the other three case managers provided services for those living in the surrounding counties (i.e., small towns and rural settings).

3.4. Data Collection. A total of 52 in-depth, semistructured interviews were conducted with clients, family caregivers, and PSWs. Each participant was interviewed two to three-times over a period of 19 months (January 2007–July 2008). At the beginning of the initial interview, participants were asked to complete a brief demographic questionnaire, and for each person with dementia, an SMMSE score was obtained to describe the level of cognitive impairment. With the exception of the focus group interview with the case managers (which was conducted at the local CCAC office) and two interviews conducted by phone, all the interviews were conducted in the home of the client and/or family caregiver. After each interview, researchers dictated full field notes about their observations, perceptions, insights, nuances of communication, nonverbal expressions,

caregiving behaviors, and interactions between and among all participants [41].

3.5. Data Analysis. Following the guidelines for data analysis of Lofland et al. [42], emerging initial codes were identified from the transcripts and the field notes. Memos were used as supplementary notes and background information to inform the analysis. After an iterative process of refining the initial codes, focused codes were applied to “clean” transcripts in an attempt to identify gaps or missing codes. The final analysis steps involved the development and refinement of the major themes, the identification of phrases that most accurately illustrated these themes, and diagramming, a process that facilitated an understanding of how the focused codes related to each other in order to conceptualize the larger picture [42].

4. Findings

Based on our analysis, three interrelated, dialectical themes were identified: (1) *finite formal care-inexhaustible familial care*, (2) *accessible resources rhetoric-inaccessible resources reality*, and (3) *diminishing care resources-increasing care needs*. Although the management of dementia home care resources is complex, study findings suggest that the lack of available, accessible, and appropriate formal care resources has ultimately contributed to the failure to provide optimal home-based dementia care.

4.1. Finite Formal Care—Inexhaustible Familial Care. Study findings revealed that the resource allocation by the formal sector depended heavily on families and friends to provide the bulk of care and assistance to persons with dementia, and only as a last resort, were formal care resources utilized to supplement this care. The notion of formal care resources as scarce commodities produced, by default, a view that familial care resources were abundant. Furthermore, the need for formal care assistance tended to be based on the assumption that family members were not only capable, but (ought to be) willing to provide care to members with dementia. Although all study participants addressed this “unspoken” reality that families provided the necessary care first and foremost, case managers were positioned to actively cultivate the availability of familial care resources. As one case manager explained:

I have a new demented person and the first thing that I did is to try to rally every family member... and gather as much family or friends that you can to start off with and focus on and get as much care in there as needed.

Care resources provided by the formal sector were viewed as supplementary “help” to the family, being made most readily available when the family member was viewed as “desperate” or in response to a crisis. In an extreme situation, one spousal caregiver explained how formal care resources were withheld until she secured the assistance of a physician:

And she [nurse] said, “Is he [person with dementia] in agony?” And I said, “Well, I don’t

know.” “Well when he gets in agony, call me back.” And I said, “I beg your pardon?” So I called the neurosurgeon... The gal on the desk answered it but she gave the phone to him, and he said, “What’s going on?” and I said, “Thomas’s catheter is plugged... and the [nurse] told me that I was to wait until he was in pure agony, and then call her back.” And he said, “I beg your pardon? Do you have her phone number?” And I said, “Yes I have.” “Well you give it to me. I’ll get back to you.” Within 10 minutes he called back... and he said, “Sit back and relax...she’s coming in.” But that kinda thing, you know? Who needs it? Nobody!

Furthermore, many family members reported feeling unheard when they expressed concerns or an inability to continue providing care. Another spousal caregiver stated that she only received “help” from the formal care system when she threatened to stop providing unpaid care:

My breathing has been terrible since I had my heart attack ... and I’ve been begging for help ... Nobody listened until now. And Jill [case manager] called me when I was trying to fix supper and I couldn’t breathe. And she said, “Joan, you don’t sound very good!” I said, “No ... Sorry Jill. I’m ready to give it up... I can’t do this anymore. This is just too hard to do.” [She responded] “Oh no! Don’t do that. No, no don’t do that!” So I received extra help... But it makes you feel you are on your knees, all the time begging for some help.

Despite the potential for “caregiver burnout”, case managers were required to distribute formal care resources within the current fiscal constraints of home care. This approach to dementia home care limited them in providing adequate support, even when familial care is exhausted. As one case manager reported:

Like that caregiver burnout, drop dead thing, the back-up plan for [the care of] these memory clients, there isn’t one. So I mean I think that’s how we can do it [alleviate caregiver burden]...four hours a week is what we’re going to provide and we do whatever we can to make it work.

Using a supplementary approach to managing dementia care resources, however, did not alleviate caregiver burden in this study. Instead, the provision of care to persons with dementia over long periods of time exhausted the capacity of most families. Expectations of families to provide complex, continuous care without adequate formal care resources disproportionately burdens families exacting financial and emotional consequences. One spousal caregiver described the devastating and costly toll on family capacity and stability.

I've got a husband at home with dementia... I cannot leave him. [My doctor asked me] "Well don't you have any family?" [and] I said, "Well, my family disowned me because I used them too much." And, it's true.

To complicate matters, the amount of formal home care available to persons with dementia and their families was often based on different interpretations of "hours available" and "need", with opinions varying amongst family caregivers, in-home care providers, and case managers. A personal support worker responded to the question of increasing the hours of home support workers as a means to provide respite for a spousal caregiver,

That [maximum amount of hours] would be 15 hours in a week. And I don't know if... CCAC would allow it... It is hard to tell. It's because that would be the maximum hours... as far as I know, it's 60 hours in a month.

Ultimately, case managers were positioned to recommend the 'appropriate' amount and frequency of formal home care support, depending on their assessment of the situation and the degree of latitude granted by their employer. Although most case managers conveyed that they followed a 'standardized approach' in the allocation of available formal home care resources, others reported that this was sometimes negotiable, depending on the needs of the family. As one case manager explained:

I'll go out to a home and they'll say "Oh, I know she [another family caregiver] gets three afternoons a week to go out and play bingo."...then I kind of have to say, "Tell me what you feel you need." Like...I'm not going to walk in and tell you that you're going to get twelve hours, it's what you need to continue doing this. So again, there's no hard fast rule.

The provision of formal home care resources for persons with dementia and their family caregivers in a timely way was also another challenge identified. There were health and safety consequences to families when formal care resources were unavailable, especially during the evenings and/or weekends. A spousal caregiver recalled a situation in which she required the assistance of her landlord during the evening to clean up after a toileting accident:

I don't know how it happened, but the walls, the toilet, everything was covered [in feces]. And he [person with dementia] is trying to get down there, not telling me, trying to clean it up. And of course he ends up with it all over him, his hands. So then he's getting the taps. So disgusting (whispers)... It took [the land lord] an hour and a half to clean that bathroom, put my laundry in for me, and I said to him, "Boy this is beyond the call of duty...And I really appreciate it." He said, "Don't worry about it"

... But it's embarrassing, not for me so much, as it is for him... but I had no one else to call!

A daughter caregiver further explicated the context of home dementia care delivery, reflecting the belief that there was only a certain amount of care available:

I mean I know everybody is stretched to the limit...Even when you do request more care you are very fortunate if you get it, because there aren't as many PSWs and nurses out there, they can make a whole lot more money in the hospitals, so trying to get a lot more care [is not realistic]...we were very fortunate that we got what we did as far as I can tell.

Furthermore, when familial care resources were limited or became exhausted, the consequences to the person with dementia were potentially life threatening, as the following quote from a spousal caregiver depicted:

... She was in the hospital twice in two months...just because I couldn't take care of her. The first time she was severely constipated, I don't know!? She was only there for a day. And then the second time, she hadn't eaten... and [was] not drinking and she got dehydrated.

In addition to providing the vast majority of day-to-day care to the person with dementia, our findings indicated that family caregivers also assumed a great deal of responsibility for managing the care of people with dementia. One PSW spoke of the coordination role a daughter played in caring for her mother, noting how this was the exception, as there were many others who were not resourced as well:

But you know, even though her mom is living independently...I think Jane [daughter] does spend a lot of time monitoring, controlling, planning, setting up her mom's appointments, you probably heard about the appointments. She regularly goes to her dentist and her optometrist and the hearing specialist and now the dermatologist... Jane is very particular about her mom's health and taking her to appointments. (Pause). You see so many other cases where that just doesn't happen or where people have been parked in an apartment by themselves and say "Well mom manages best as she can" and they just don't manage.

Some people with dementia were also aware of how their families provided and managed their care. One woman remarked that her daughter coordinates her care which she finds helpful:

She gives a lot... just in her own way...I don't know how she remembers all those things said in that book... Well it's quite a bit to remember. She's gotta have everything just so!

In summary, the approach to care resource management was a supplemental model of care wherein formal home care resources were positioned as finite and precious commodities while family resources were viewed as “cost-effective” and inexhaustible. Many families, however, did not have the available resources, time or skills to assume the care management of people with dementia living at home, and yet, that was what was expected of them in view of the limited formal care resources. Moreover the management of care resources, formal or familial, was particularly challenging if the resources were inaccessible.

4.2. Accessible Community Resources: Reality or Rhetoric? Although caregivers, providers, and case managers spoke about the importance of accessing a variety of community dementia care resources, many family members did not know which services existed or how to access them. Our findings also identified many barriers that prevented existing services from being accessible, such as long waiting lists (e.g., respite), rigid eligibility criteria (e.g., home care support), or cost of services (e.g., transportation, adult day care programs).

Services were not only difficult to access in a timely manner, but were often transient or nonexistent. For instance, many participants spoke about the need for accessing appropriate respite services, both in-home and within day programs. The case managers, however, claimed that the actual provision of respite was challenging because there was never enough respite to meet the needs of families when they actually need it. Therefore, it was not uncommon for families to have to book six months or more ahead of the time the service was required. One son spoke about the lack of access to appropriate, timely resources for this father (person with dementia) at a time when his family needs were the greatest.

...I was there that summer and I do recall a lot of our hard times trying to get that extra help. Trying to increase the time for my father . . . Like it would take a burden off and then she [mother] could do some of the stuff that needed to be done around the apartment. . . I can tell you if, there was ever a time where you need a lot of help, that was it . . . I think that was a really bad example of how the system [didn't work]. . . I don't think it worked great at all.

Accessing care resources in a timely way is also compromised by systemic barriers, such as the hierarchal structure of the home care system, busy caseloads, and infrequent contact between home care providers. For instance, if personal support workers had any concerns or questions, they are instructed to contact their managers at their specific agency, who, in turn, contacted the CCAC case managers. For example, one PSW encountered difficulties in contacting his case manager to discuss a proposed increase in his hours due to deterioration in the health of the family caregiver.

I leave her [agency manager] notes if I have a concern, and sometimes I've even called her

with things. At least I tried to get through. She's very hard to get through to. . . she never seems to answer her phone. . .

In another situation, the spousal caregiver felt it necessary to make the drastic decision to move to another apartment building, so her husband could continue to receive care from the same home support worker when their “catchment area” had been rezoned. As her daughter explained:

Bobby [PSW] seemed to be a real big help in our family and when his territory was, changed, my mother and father moved so that they could maintain support and not have to go to a new person. Because she just did not want to lose that support, and my dad seemed to respond to him.

There was also a discrepancy between what case managers *said* was accessible, and the care experiences of persons with dementia and their families as they tried to access home and community care services. Interestingly, case managers described how they assisted caregivers in navigating the system to access services, which was in direct contrast to family members' stories of the difficulties they encountered and the lack of support they received. As one case manager explained:

As a case manager it's my job to help with system navigation, to help them access [resources/services], tell them what's available, but to let the caregiver make decisions as to what they feel they need as they progress, and to support them through this journey.

And yet, as a daughter caregiver elucidated, bringing support into the home was neither a transparent process, nor, at times, a user-friendly activity:

...If the support can be easily brought into. . . the home then I think that is preferable than taking a person out of the home. . . I don't think there is any comparison . . . and when I say easy [to navigate the system], I also mean like just the process itself who—who to call, how to do it and not make it a challenge or a huge difficulty for the family or the caregiver.

When formal care services were provided in a standardized and regimented way, they were often described as inadequate and substandard. Older adults and their families struggled to acquire additional, essential resources to fill in the substantial gaps left by the formal system. Families who were without access to appropriate, timely home and community services were particularly vulnerable. As one daughter caregiver described:

You know that was an additional expense [house cleaning] and I couldn't pay for it . . . [So] now they come every 2nd week, so things like that, house cleaning which seems to be really basic care, are huge . . . help because it's just that much

time and energy that she [spousal caregiver] doesn't have to spend on something you know, where she's probably already exhausted.

Those who could not afford to buy additional supports were also less likely to complain about substandard or inept in-home care for fear of not receiving any assistance. As one spousal caregiver explained:

You just aren't comfortable saying it's poor care because I didn't think I'd get anyone else. . . And I couldn't go with nothing. . . So it was, "hang in there".

Thus, although the rhetoric of the system of home health care suggests that resources essential to quality home based dementia care are universally accessible to persons with dementia and their families, unfortunately, our findings illuminate that this assumption is more rhetoric than reality.

4.3. Diminishing Care Resources-Increasing Care Needs. The final theme reflects the temporal nature of care resources, whereby diminishing care resources occurred, while care needs are simultaneously increasing. The adequacy of resources was often assessed on what types of formal and familial care resources were available in the past, and if they met the current needs of the person with dementia, without adequate provision for future care. As a son caregiver clarified:

She [mother, caregiver of father] has Mark [PSW] here, and she's paying [a housekeeper] to come in and take care of the basic stuff. So, as long as those things remain and everything stays the same, then those would be the key components to make it work. If those disappeared, then I think it would. . . throw her out of whack, actually. I mean, I know that I can't keep coming in here every day.

The preceding quotation illustrates how formal care resources needed to be monitored on an ongoing basis because the demands of care as well as the familial resources often change over time with the progression of the disease. Spousal and adult child caregivers may become physically and emotionally depleted, and financial resources may run low. Therefore, given the cumulative effects of dementia care giving, the same level of resources and services may be no longer adequate or readily available. A daughter caregiver described this shift:

We, we've come to realize in the last year, that my dad's health has changed more significantly than it had previous to this last year and my mom's physical capability and mine. . . you know, we're not big strong people who can make sure he gets bathed properly and that kind of thing. We don't have all the appropriate facilities. It would be great if we had all the money in the world and we could build a big huge house to keep

everybody with all of the sort of facilities and handicap services and everything. That would be great, but that's just not a reality.

Challenges in providing care are therefore exacerbated when there is a constant risk that the resources presently available will cease to be available or will become *inadequate* as dementia progresses. What may have been adequate at one point is no longer adequate at another. As one PSW explained:

I find they [family caregivers of persons with dementia] need more help than they're getting now whether it's PSW hours or hours with the nurse or some type of a counselor going in there assessing situations more often. . . More people could be kept out of institutions if they had a little bit more home help. . . more resources, more people watching, more people, some sort of a method where people are on top of the situation more.

There was also a sense of collective resignation amongst families, providers, and case managers that the current dementia home care system was the "best it can be." One case manager described her sense of powerless:

I think when I first started out as a case manager, especially with dementia care patients, I really had to learn that you should let go and sometimes things will just be the way they are. . . you can only do so much. I call it "crash and burn". If somebody is going to crash and burn, it's going to happen and *there's only so much you can do*. That was a hard thing to let go of, because we like to help, you know, we like to fix, but some things, we can't fix.

These words reflected an implicit assumption that the formal care system is there to "help" families who do not or cannot provide the bulk of care for persons with dementia. This reinforces the notion that the care of older adults in the community is a family issue, instead of being viewed, at least in part, as a system failure that requires a different approach to dementia home care.

5. Discussion

Dementia home care was portrayed by persons with dementia, caregivers, providers and case managers in nine dementia care networks as three interrelated, dialectical themes: *finite formal care-inexhaustible familial care*, *accessible resources rhetoric-inaccessible resources reality*, and *diminishing care resources-increasing care needs*. The study findings suggest that unless familial and formal home care resources are reconceptualized and managed differently in the future, the needs of persons with dementia and their family caregivers will be drastically compromised. The study findings reflect the experiences of clients, family caregivers, and providers who were primarily white, Anglo-Saxon, and therefore,

cannot be assumed to reflect the experiences of persons from varied ethnic backgrounds. In spite of this limitation, these findings provide several insights for future directions in home care practice, policy, and research.

5.1. Relationships between Formal and Familial Care Systems.

A home care system that depends so heavily on familial care should recognize families as indispensable partners in dementia home care, not resources to be exploited [30, 43]. Concerns that formal care services will drive out the unpaid family care must also finally be put to rest because we know from this study and from others [35, 44] that this is not the case. Indeed, study findings suggest that the abilities of families to sustain these high levels of care may well exceed their resources in the future [45]. As Levine [46] aptly argues, “the ongoing push toward a health care system that uses public resources sparingly and family caregivers liberally” is no longer viable. However, as long as the sociocultural assumption that family care resources are unlimited and exploitable remains intact, policymakers will not likely view support for caregivers as a wise and prudent decision [47]. Therefore, by reconceptualizing the relationship between formal and informal care systems to one that is collaborative rather than supplemental and potentially exploitive, we begin to open up possibilities to create a more equitable environment for dementia home care.

Study findings also revealed that the taken-for-granted assumption of finite formal care and inexhaustible family care is particularly difficult for families with limited financial and familial care resources. Their energy and capacity to provide care became depleted at the time when family caregivers needed them the most—as their relative’s cognitive ability progressively declined. While there are several clinical assessment tools to measure caregiver burden [48], the family’s “capacity” to provide and sustain long-term home care was rarely considered in our study. This finding suggests the need to change the current home care policy to one in which case managers are allocated the time and tools to carefully and routinely assess the family’s capacity to provide dementia care over time, with the ultimate goal of delivering individualized, comprehensive formal care services to persons with dementia and their families, particularly in the later stages of the disease.

Although the inequitable distribution between formal and familial care results in substantial costs to caregiving families [49], these financial expenditures were rarely acknowledged in this study, a finding that is consistent with previous investigations [47, 50]. As the purse holders or gate keepers of the system [38], the case managers focused on the costs of *formal care* services, which were carefully assessed and allocated according to the “medical needs” of the client. Furthermore, the family caregiver, not the case manager, tended to be the primary person who managed the care resources, but with limited or no authority to ensure optimal care. In light of the study findings, it is not surprising that caregiver burden is inherent in this supplementary care model that overuses familial care resources to the point of exhaustion. Unfortunately, improving formal care services in ways that may enhance the quality of life of caregivers and

those they care for tends to receive low priority in the current policy culture. Despite the benefits of reducing family care burdens by providing available and accessible formal care [47], the expectation that families not only must, but also ought to cope with minimal if any formal care continues to exist in a context of home care where the responsibility for care continues to shift from the state to individual families.

This expectation for family caregivers to deliver the bulk of dementia home care is not only shortsighted, but unaffordable. As dementia rates continue to rise, the costs of providing care to persons with dementia living in the community warrant increased attention [9]. Offering choice on how to manage their care may both lower the costs of home care and enhance client independence [51, 52]. Therefore, the current case management approach may potentially undermine both client and family involvement as well as position family caregivers in precarious financial and emotional situations. More research on the economics of caregiving is necessary, not only to fully understand the financial and social costs incurred by families, but also to identify what supports families need today and in the future.

To ensure adequate provision of formal care resources, however, equal attention must be paid to the recruitment and retention of a strong home care workforce. The current shortage of home care workers is troubling [23, 26]. Research efforts to understand the work issues and working conditions of home support workers and nurses are critical in understanding human home care resources in the future. Furthermore, we need to better understand how to attract and retain these workers [12, 26, 46], as well as how to promote collaborative relationships between and among clients, families, home care workers, and managers if we hope to address this issue in the future. In addition, a change from home care policies and practices that contribute to the vulnerability of home care workers to ones that give them the recognition and remuneration they deserve is overdue [12]. Thus, the identification and implementation of necessary policy and practice changes can hopefully create a space for familial and formal caregivers, many of whom are women, to begin to develop and enjoy a meaningful, collaborative caregiving relationship. Ultimately, the joint efforts by persons with dementia, practitioners, family caregivers, and policy makers will lead to an improved and equitable relationship between formal and familial caregivers and the systems they represent.

5.2. Accessibility of Home and Community Resources.

Similar to other studies [53], our findings illustrated that inequitable access to formal care resources has contributed to the strain that familial caregivers experience while trying to cope with the demands of providing care. A consistent theme in the research literature is that people who might benefit from respite care do not use these services or only in small amounts [54]. The utilization of certain services is due to many contributing factors, but amongst the most prevalent reasons are ones that were revealed in this study: family caregivers are not made aware that the services exist, and existing programs are inaccessible, inconvenient, or expensive [53]. This finding highlights the importance

of families knowing the number of formal home care hours that are available to them, the need for a formal, targeted system of communication, and awareness/education programs for caregivers. Furthermore, formal care services based on symptoms and disability assessment are not always related to an individual's actual care needs. For instance, an individual with a moderate level of dementia may have fewer unmet needs because they were able to be met by their care environment, whereas a person receiving higher levels of assistance may have many of their needs left unmet because of low levels of personalized care [55]. There were also marked differences with respect to resources within and available to the networks in our study, yet they were treated as though they have the same access to resources. As opposed to adult children, spousal caregivers may not have the same resources such as health, information, and confidence, or families who live in rural areas [56]. This study finding is congruent with those of others who have raised concerns about equitable access to home care services [50]. Thus, flexible programs and services must be offered if the needs of all families are to be met, irrespective of their composition or where they reside.

Similar to Pratt et al. [57], we found that increasing access to services involves considering the wider social context of caregivers and their relationships with, among persons with dementia, other caregivers and professionals in order to more meaningfully understand issues of access. One model that takes social context into account is the integrated, continuing care model as proposed by Forbes and Neufeld [58]. This type of model is only likely to work, however, if it is sufficiently flexible to accommodate the divergent needs of persons with dementia and their caregivers in a heterogeneous society. Rather than placing the onus on families to provide the vast majority of human resources, a preferred approach is to view the care of persons with dementia as care that involves the equitable, not equal, distribution of resources. Furthermore, integration of familial and formal care is desirable only if it involves a genuine partnership between those who provide care, and not just a blurring of their respective roles. According to Blustein [59], the family is a system of care whose values, attitudes, and practices distinguish it conceptually, ethically, and emotionally from other sorts of care relationships, and any "partnership" between the two systems which integrates the values of formal and family care should be one that recognizes and preserves these differences. In addition, there is a need to respect the differences, as well as the commonalities, between formal care and family care, otherwise no one is well served. Therefore, a new home care model is needed that not only includes persons living with dementia and their family caregivers as genuine partners in care, but also embraces diversity, flexibility, real choice, and supportive services, within the context of a national home care program [50, 54].

5.3. Organization and Delivery of Dementia Home Care Resources. Clearly, we need new ways to think about and manage dementia home care resources. At the very least, families must receive the support services they require

to prevent their need for costly specialized services and premature institutionalization of the person with dementia or their caregivers [60]. Furthermore, if we hope to address the challenges of dementia home care in the future, it is important to reorganize the ways in which home health services are funded, organized, and delivered in Canada [9, 50]. Funding must be provided so that there are necessary resources to enable home care programs that meet the long-term needs of persons with dementia and their families. Just as other provinces, jurisdictions, or nations that count on the home care system to alleviate acute resource constraints must, the time has come to move beyond the current four percent-funding formula of the health care budget allocated to home care [61] and to adequately fund Canadian home care programs [54].

As in other neoliberal states where austerity measures reduce the resources available for social and health care, Canadians have witnessed in the last fifteen years the offloading of once public social programs to mixed economies of public, private, and for-profit welfare [62]. Major shifts in health care financing and home care reforms have led to fewer home care services at the same time that case managers and direct care providers have larger case loads of clients with more complex needs. Study findings have illuminated a common theme of competing priorities and little time, with case managers negotiating the competing roles of advocate and service gatekeeper. Similar to Aronson and Smith's study [62] of social service managers in southern Ontario, study findings illuminate the "quiet" resistance of case managers and how they struggled to respond to the shrinking formal care resources available to them. Very few case managers took on an active advocacy role in our study; however, they did not passively accept their situation in this restructured environment. Although the personal support workers and managers talked about their limited abilities to respond to the structural inequities experienced by the family caregivers, a number of them employed certain strategies to 'get around' the perceived unjust practices and policies inherent in the system. Therefore, it is important in future research to explore the structural barriers that disable case managers and other home care workers in advocating for equitable home care practices that would enable aging in place in later life.

6. Conclusion

With the shrinking welfare state, the notion of optimal care has been replaced by discussions around whether services are available/unavailable, accessible/inaccessible, and adequate/inadequate; however, all three are interwoven such that without available and accessible services, services cannot be considered adequate. Home-based dementia services must, at the very least, provide care resources that are accessible *and* available in order to be considered adequate. As our findings illustrate, people who have the least amount of resources and the least amount of accessibility are the ones most struggling with inadequate care resources. Consistent with Jenga, a board game of balance, these networks are often teetering on

the brink of collapse, and as long as they do not fall apart then the resources are perceived to be adequate. This current supplementary model of dementia home care is not only unjust, but it is also not sustainable in the future.

Study findings suggest that we need to engage in critical dialogue and working toward policies and practices that will result in available and accessible resources to ensure optimal “aging in place” home-based dementia care. To meet this goal, we must first challenge the current assumption that formal care is finite and family care is inexhaustible. Home care practices and policies need to take into account the family’s capacity to provide complex care over time. Second, the provision of available and accessible resources, including respite, programs, and home support workers, is essential to support families who provide this care [4, 20, 58]. Furthermore, families require, at a minimum, clear and honest information on how to access resources. Third, formal care providers need to actively advocate with caregivers for equitable distribution, not equal distribution of formal care resources. Finally, family caregivers, formal care providers, policy makers, and researchers need to share a common vision for home care resource management and collaborate in order to optimize the health of clients and families in home-based dementia care as they age in place now and in the future.

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Research Article

Revisiting the Role of Neighbourhood Change in Social Exclusion and Inclusion of Older People

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Objective. To explore how older people who are “aging in place” are affected when the urban neighbourhoods in which they are aging are themselves undergoing socioeconomic and demographic change. *Methods.* A qualitative case study was conducted in two contrasting neighbourhoods in Montréal (Québec, Canada), the analysis drawing on concepts of social exclusion and attachment. *Results.* Participants express variable levels of attachment to neighbourhood. Gentrification triggered processes of social exclusion among older adults: loss of social spaces dedicated to older people led to social disconnectedness, invisibility, and loss of political influence on neighbourhood planning. Conversely, certain changes in a disadvantaged neighbourhood fostered their social inclusion. *Conclusion.* This study thus highlights the importance of examining the impacts of neighbourhood change when exploring the dynamics of aging in place and when considering interventions to maintain quality of life of those concerned.

1. Introduction

A number of researchers have suggested that with advancing age, a person's geographical area tends to become increasingly limited in space [1–6]. Research that has explored the question of the meaning of place in different groups indicates that proximity of neighbours has a greater importance in the lives of older residents [7]. The neighbourhood is more significant for older people and the disadvantaged than for the younger and more affluent, who tend to develop social networks more diffuse in space [8, 9]. (Following current conventions, we use the terms “older person” and “older adult” in reference to people aged 65 years and over.) Moreover, the neighbourhood and the “home” become key elements in social life—social relations gradually become limited to people who live nearby—and also in defining one's sense of self, because the neighbourhood provides a number of identity markers [10]. Older people tend to be more reliant on their immediate environment as they are

less likely to be involved in employment and have greater chance of becoming physically dependent [11]. Despite the growing body of aging-in-place research, social gerontology, hampered by static “environmental fit” models [12] has paid relatively little attention to the changes taking place in the neighbourhoods within which older people are aging and to how they experience these changes (submit to? actively participate in?...). It has been largely up to researchers in the geographies of aging to demonstrate the importance of neighbourhood change. Moreover, the social gerontology literature on aging in place and on the role of place in aging in old urban neighbourhoods—including a notable recent UK-Canadian comparison [13]—still focuses predominantly on neighbourhoods experiencing observable physical decline or mounting criminality. The latter could have negative impacts on older people's comfort level in their homes or on their ability to appropriate and navigate local public spaces [14, 15]. This focus is not surprising given that living in neighbourhoods of “multiple deprivation” can potentially

reinforce the social exclusion of older people. However, it is also important to uncover possible dynamics of social exclusion of older people who find themselves living amidst growing affluence where they experience forms of place reshaping largely beyond their control, as in the case of neighbourhoods undergoing gentrification [16].

Gentrification is simultaneously a physical, economic, social, and cultural phenomenon classically defined in the literature as involving the “invasion” of previously working-class neighbourhoods by middle or upper-income groups and the subsequent displacement of many of the original residents [17]. (The use of the term “invasion” intentionally evokes the notion of invasion and succession developed by the Chicago School of urban sociology.) Debates and empirical research surrounding this topic now amount to a vast body of scholarship in urban geography and cognate fields; indeed, gentrification is often seen as the most important type of urban change across the global North over the past three decades [18]. This process involves a change in population characteristics with the arrival of younger, better educated people with higher incomes, a significant increase in the cost of housing (including house values, rents, property taxes), particular styles of commercial revitalization, increased traffic on neighbourhood commercial streets, and finally, displacement of former residents to more affordable neighbourhoods.

Over the past 15 years or so, the forms taken by gentrification have diversified [19]. While private-sector actors (e.g., home renovators, landlords) still cause displacement, core city municipalities of large metropolitan areas are increasingly courting, even orchestrating gentrification. For example, they may facilitate new housing construction and the rebranding of neighbourhood commercial arteries [20, 21] so as to relaunch local economies, resolve fiscal crunches, and attract young and urbane singles and/or families, such that in some cases the long-standing trend for demographic aging of the innercity has been dramatically reversed. Consequently, scholarly debates are increasingly seeking to conceptualize and shed light on the various forms of “indirect” displacement that may be created when an existing population is not literally forced out of an area—because they live in social housing or are otherwise protected from displacement in the literal sense—but their local cultures and narratives of place, their access to familiar services, or their channels of local political representation are disrupted by the influx of younger, more educated and wealthier newcomers [22–25]. A complementary insight from the social determinants of health literature [26] is that discrepancies between personal income (low) and neighbourhood status (high) can be associated with poor health, especially for older people. These trends create a need to deepen our understandings of how gentrification can affect older people.

Empirical work on its indirect negative effects on older people is as yet very sparse, but with a few insightful exceptions, such as that of Lehman-Frisch [27] alluding to commercial gentrification’s culturally and economically exclusionary impact on long-term older adult residents of San Francisco and findings from Toulouse, France showing

how neighbourhood revitalization may generate among older adults a sense of being out of place to the point that they are reluctant to venture out of their house [3]. In contrast, little attention has been paid to the potentially positive experiences of some older people in contexts of gentrification [28]. For instance, with gentrification comes an increase in real estate assets and it may give a greater sense of security due to increased numbers of people on local shopping streets, improved public facilities and services, and more opportunities to meet people. For these reasons, we decided to launch a study to explore older adults’ perceptions of gentrification and to determine its effects on both their social exclusion and inclusion. Drawing on concepts of social exclusion, direct and indirect displacement, and attachment, this paper addresses how older people experience change in two contrasting neighbourhoods in Montréal, Canada: (1) La Petite-Patrie, a rapidly gentrifying neighbourhood and (2) Lower Notre-Dame-de-Grâce (NDG), a disadvantaged neighbourhood. This study forms part of a larger qualitative research project aiming to better understand the ways in which gentrification can contribute to the dynamics of social exclusion and inclusion of older people. As well as the Montréal study areas, the research has an international comparative dimension embracing two neighbourhoods in Toulouse, France (Minimes and Marengo). (A comparison including the two French neighbourhoods is beyond the scope of this paper.) The aims of this study were to answer the following questions.

- (1) What place does the neighbourhood have in the everyday lives of older residents? (What places do they frequent? Where are their social networks situated? What neighbourhood resources and services do they use?)
- (2) What neighbourhood changes do older residents notice?
- (3) How do neighbourhood changes affect older residents’ experiences of social exclusion/inclusion?

2. Theoretical Framework

2.1. Social Exclusion. This research project is framed primarily by a conceptualization of the dynamics of social exclusion [29]. Social exclusion originated as a sociological concept, emerging from European policy circles, especially in the 1990s [30, 31] extending into gerontological research and public policy debates, especially within the context of the United Kingdom [14, 15, 32–34]. More recently, Billette and Lavoie [29] define social exclusion as a process of nonacknowledgement and deprivation of rights and resources of certain segments of the population (in this case, older adults) that takes the shape of power dynamics between groups with divergent visions and interests. Such processes result in inequities and lead eventually to isolation from society in seven dimensions: (1) symbolic exclusion (negative images, overrepresentations, and invisibility); (2) identity exclusion (multiple identities are dismissed and a person’s identity is reduced to belonging to one singular group,

for example, “old”, “frail”, “burdensome”); (3) sociopolitical exclusion (barriers to civic/political participation); (4) institutional exclusion (reduced access to services); (5) economic exclusion (lack of financial resources); (6) exclusion of significant social ties (absence/loss of social network); (7) territorial exclusion (reduced geographic living area, unsafe neighbourhood). Billette and Lavoie’s definition puts forth two essential characteristics of social exclusion. First, it is a dynamic, fluid process rather than a static state. Second, since it is a multidimensional concept, it allows for a rich understanding of how social exclusion can be experienced across many facets of a person or population’s life. For instance, in relation to gentrification, increases in rents and the changing commercial landscape may put financial strain on older people, especially those with modest incomes (economic exclusion). Older adults could also lose their political influence in relation to social planning (sociopolitical exclusion). The arrival of younger, more educated populations can reinforce certain stereotypes of older people, such as “slow”; “nosy”; “busy-bodies” of the neighbourhood (symbolic exclusion). Leaving a familiar neighbourhood or having friends and neighbours move away can also lead to social network exclusion. The dimension of territorial exclusion is of particular interest because neighbourhood change involving gentrification could lead to feelings of insecurity as familiar institutions disappear and the public spaces of everyday life take on a new look and “feel.” Territorial exclusion also shares dimensions with the useful geographic concepts of direct displacement (physically forced out of one’s neighbourhood) and indirect displacement, as described above.

2.2. Attachment to Place. The concept of attachment is central to understanding how urban change can affect older adults. An individual’s level of attachment to their environment will have a direct impact on how changes are experienced and perceived. This is especially the case for older people because, as mentioned above, the immediate environment becomes more important with age [8, 9]. Older people develop a sense of self-attachment, personal identity, and social differentiation through the relationship they construct and maintain with daily, “ordinary” spaces [35]. Therefore, understanding older people’s attachment to place becomes a crucial element to understanding how they experience neighbourhood change.

It is important to make the distinction between place and space. Space refers to the physical location, whereas place can be thought of as a process and includes an integration of physical, social, emotional and symbolic aspects, interacting in different degrees [6, 36]. Several authors have since written on attachment to place [37–41] dating back to the path-breaking work of Rowles [42, 43] who developed a theory of *insideness* to conceptualize attachment to place, using three components: (1) autobiographical; (2) physical; (3) social. For Rowles, physical insideness is associated with living somewhere for long periods of time—the resident establishes a sense of environmental control or mastery by creating an idiosyncratic rhythm and routine. Social insideness evolves

not only from everyday social exchanges and relationships but also from a sense of being well known and knowing others. Third, autobiographical insideness has been suggested to be the most relevant to describe older people’s attachment to place because it is embedded in memories. As we age, these memories are recalled selectively in the creation of one’s identity. Older people with strong ties to place are also reported to feel more in control, more secure and to have a positive sense of self. Attachment to place has also been studied by Rubinstein and Parmelee [40] and more recently by Sugihara and Evans [44] who make the link between older people’s attachment to their dwelling, maintaining a positive self-image and maintaining their independence. Overall, in the past 30 years the study of attachment to place has captured the attention of scholars from geographical, gerontological, and environmental psychology perspectives [6, 37, 39, 45, 46], yet to date little has been written on what occurs when older people, who are aging in place, experience a neighbourhood that is itself undergoing change [14].

3. Methods

3.1. Study Design and Sample. We situated our research in an explorative, qualitative case study design [47], cases being the changing neighbourhood, the unit of analysis being the older person’s personal experience of neighbourhood change. Case study methodology is suitable for studying complex and multifaceted social phenomena embedded in specific contexts [48]. Our overarching research question is concerned with how older adults experience different types of neighbourhood change, especially those involving gentrification. Exploring this complex issue necessitates recourse to multiple sources of evidence (e.g., document analysis, interviews with older people, and key informants), which is typical of case study methodology in the social sciences. For the Montréal component of the research, we selected two inner-city neighbourhoods (see descriptions below) where local community stakeholders were concerned about current or impending gentrification and how it could affect older people. Following a complete ethics review process by two university ethics boards (covering informed consent, confidentiality, respect, risks, and benefits, etc.), we conducted 30 semistructured face-to-face interviews with autonomous and mobile older adults aged from 68 to 95 years. All of our participants had lived in one of the two Montréal neighbourhoods for at least 10 years or did live previously there but had moved away in the past five years. We included private renters, homeowners, and people living in residences for autonomous older adults. We also conducted 10 in-depth interviews with key informants (i.e., six in La Petite-Patrie and four in Lower NDG, who came from varied backgrounds (e.g., municipal councillor, priest, community workers, etc.)). Table 1 summarizes some key characteristics of the older adults who participated in this study.

3.2. Data Collection. Participants were referred from a variety of community organizations (e.g., a tenant advocacy organization, the local community health care centre in both

TABLE 1: Profile of study participants ($n = 30$).

	La Petite-Patrie	Lower NDG	Total
<i>Total participants</i>	18	12	30
Men	6	5	11
Women	12	7	19
65–69	1	0	1
70–74	1	3	4
75–79	8	3	11
80–84	4	1	5
85–90	3	3	6
90+	1	2	3
<i>Mother tongue</i>			
French	12	0	12
English	0	5	5
Italian	6	7	13
<i>Highest level of education*</i>			
Primary school (incomplete or complete)	8	7	15
Some high school	5	1	6
High school (completed)	2	1	3
Postsecondary	2	2	4
<i>Socioeconomic status</i>			
Low income [#]	9	3	12
<i>Current residents</i>			
Owners	5	9	14
Renters	13	3	16
Renters living in HLM (public housing) [∞]	4	1	5
<i>Former residents</i>	5	1	6
<i>Years in neighbourhood[§]</i>			
Less than 30 years	5	4	9
30 to 39 years	7	2	9
50 years and over	6	6	12
Total	18	12	30

* No information for two participants, one in each neighbourhood.

[#]For the study purposes, low-income participants are those receiving the guaranteed income supplement (GIS), which provides additional money to top off the Old Age Security Pension. The maximum annual income for a single person GIS recipient is \$15,960 (Service Canada, Old Age Security Payment Rates, April-June 2011: <http://www.servicecanada.gc.ca/eng/isp/oas/oasrates.shtml>). This definition is more stringent than Statistics Canada's low-income cut-off of \$22,229 before tax in 2009 for a single person living in a city of more than 100,000 inhabitants (Statistics Canada, Low Income Lines 2008-2009: <http://www.statcan.gc.ca/pub/75f0002m/2010005/tbl/tbl02-eng.htm>).

[∞]HLM (Habitations à loyer modique) are apartment complexes for low-to-modest income households, owned and managed by the public sector. Rent is set at 25% of household income and includes basic utilities. Tenants are selected from a waiting list according to needs-based criteria established by the provincial government. Those in our study are specifically for autonomous older adults.

[§]Lowest value of years in neighbourhood is 9 years followed by 12 years; all others resided in neighbourhood over 15 years.

neighbourhoods, and the NDG Senior Citizens Council). Our research assistants put up posters in businesses and distributed pamphlets and presented the project at various social events for older people. We encountered important challenges recruiting individuals displaced as a result of gentrification (this is a widespread problem in gentrification research [11]). Although we had partnered with a tenant advocacy organization in La Petite-Patrie that was willing to refer recently displaced clients, this strategy only generated one interview. In Lower NDG, the Senior Citizens Council had also hoped to refer recently displaced members but

was unable to locate former residents who had maintained ties with the Council. Other prospective participants were ineligible or not interested for various reasons (e.g., did not meet age requirements, insufficient length of residency, poor health). Attempts to recruit displaced individuals using the snowball method were also unfruitful. We also contacted several autonomous residences for older people in adjacent areas of Montréal, but their administrators were not willing to participate in the study. In sum, in La Petite-Patrie we interviewed five displaced residents. In Lower NDG, we interviewed one long-term resident who had recently left.

However, only one of the displaced participants was forced to leave because of a housing takeover, all of the others moved due to declining health.

Interviews were conducted in English, French, and/or Italian, lasted between 60 minutes to two hours, were voice recorded and transcribed in their entirety, the Italian material being subsequently translated into French. The original French language interview guide was developed in collaboration with our French colleagues and upon completion was translated into English and Italian. Our interviews aimed to explore what changes older residents perceive as having occurred in the neighbourhood (e.g., new constructions, population, neighbourhood image, etc.) and what the effects have been on them. Some of the potential impacts were covered systematically: social networks, change in urban landscape (e.g., loss/gain of new businesses, new constructions). We also wanted to explore to what extent older people's social networks and activities were located inside and outside of their neighbourhood, to be able to evaluate the significance of the local neighbourhood. Finally, we were interested in what place older residents see for themselves in the neighbourhood, how they feel about aging in place, what keeps them in their home. The interview ended with a brief sociodemographic questionnaire to better contextualize their perspectives.

The key informants were interviewed using a semistructured interview guide and informed consent was obtained before each interview. The interviews lasted between 45 minutes to one hour and were voice recorded in their entirety. Participants were asked to describe the neighbourhood (types and cost of real estate and rentals, population, transportation, cultural activities, businesses, etc.). They were then asked about any changes they had noticed (new constructions, population, etc.). Finally, they were asked specifically about the role that older adults have in the neighbourhood and whether they believe the neighbourhood is a good place to age. The term "gentrification" was purposefully excluded from all recruitment material and the interview guides so as not to bias participants' responses.

3.3. Analysis. All interview transcripts were read, and an analytic summary was created for each participant to understand the situation and the dynamics of social inclusion/exclusion of each of the participants. The analysis employed both deductive and inductive approaches in identifying themes to generate an understanding of how neighbourhood change was experienced in the everyday lives of older adults. The seven dimensions of the social exclusion framework [29] (symbolic, identity, territorial, sociopolitical, social network, economic, and institutional) were employed for the first round of the deductive coding. To obtain a better understanding of the participants' perspective, we also used Rowles' three components of attachment (physical, social, and autobiographical). To avoid forcing material into predefined categories and to reflect themes emerging from the data, we generated codes inductively using the grounded theory approach of Glaser and Strauss [49]. These inductively generated codes were reviewed and discussed

until the research team members arrived at a consensus. The entire analysis process was facilitated by using the qualitative software package QDA Miner.

4. The Two Study Neighbourhoods

Before moving on to the presentation of findings, we now briefly introduce the two neighbourhoods, referring to a summary table showing how their sociodemographic characteristics evolved over the decade preceding the start of our fieldwork (Table 2).

4.1. La Petite-Patrie. La Petite-Patrie is a working-class inner city district a few kilometres north of downtown Montréal and dating from the 1910s–1920s when it was considered part of a larger suburban district called Villeray. It is mainly French-Canadian in ethnocultural composition but is also home to one of the founding parishes of the city's Italian-origin community. In the 1970s and 1980s its ethnocultural profile diversified with the settlement of Latin American and Southeast Asian immigrants. It is known citywide today mainly for two major culinary attractions in its western sector: the Jean-Talon produce market and the Little Italy commercial strip on nearby St. Lawrence Boulevard, both of which have been the object of large municipally led revitalization initiatives in the past 10–15 years. Little Italy has undergone a "rebranding" through ethnic entrepreneurship and many of the traditional storefronts on the main shopping street have been renovated and given way to more luxurious boutiques. Although the resident population of Italian ethnic origin has shrunk by half from 1996 (5%) to 2006 (2.5%), the local Italian business community is still powerful and Little Italy remains a draw for Italian-origin residents of Montréal and upper-middle-class consumers alike. The market has been somewhat reoriented toward regionally produced and artisanal specialty foodstuffs although a vast array of fresh produce is still available.

Bucking the societal-scale trend of an aging population, this area is now home to fewer senior citizens than a decade or so ago, and their relative weight has also diminished (Table 2). It remains ethnically diverse, although the visible minority population has fallen, especially in the sectors most touched by the commercial gentrification that has been the key change in this area over the past 15 years or so. La Petite-Patrie has seen a rapid increase in residential gentrification activity since the early 2000s, in part due to an overflow from the city's two most gentrified districts, to which it is adjacent. Housing market changes symptomatic of this gentrification are increased rates of homeownership (Table 2), spiralling real estate values (especially since the mid-2000s, according to our key informants), mushrooming infill condominium construction, and conversions of rental units and nonresidential buildings (including an iconic church) to condominiums, including some up-market housing units. Our community-based key informants claim that transformations of existing rental units have generated displacement in spite of the safeguards of tenants that are in principle built into law. As well, the neighbourhood has

TABLE 2: Basic Sociodemographic data, Montréal Census Metropolitan Area (CMA), Lower NDG, and La Petite-Patrie, 1996 and 2006.

	Montréal CMA		Lower NDG		Petite-Patrie	
	1996	2006	1996	2006	1996	2006
Total population	3,326,510	3,635,571	9,553	10,284	15,792	15,423
Variation %		+9.3		+7.7		-2.3
Population 65 and over	400,135	495,690	1,110	1,120	2,025	1,740
% of total population	12.2	13.6	11.6	10.9	12.8	11.3
Population 20 to 44	1,338,110	1,313,615	4680	4995	7735	8225
% of total population	40.2	36.1	49.0	48.6	49.0	53.4
% with university degree	15.4	21.0	21.1	29.8	15.4	31.3
% low income households	27.3	21.1	45.6	41.8	58.6	40.4
Average total personal income ratio (CMA = 1.0)	1.0	1.0	0.75	0.74	0.60	0.72
% of private dwellings owned	48.5	53.4	19.0	20.3	15.5	18.5
Visible minority population	401,420	590,375	2,695	3,605	4,150	3,730
% of total population	12.2	16.5	28.7	35.8	26.5	24.4

Source: Statistics Canada, Censuses of 1996 and 2006, 20% sample data. The data for the case study neighbourhoods were calculated by aggregation of data published at the census tract level of geography.

seen an influx of a younger, highly educated population, the average incomes of its residents, while still modest overall, have increased relative to the metropolitan area average while the proportion of low-income households has fallen (Table 2). Two community organizations that have supported our project see these changes as creating pressures on low-income renters and are especially uneasy as to whether residents in their 70s and older will still have their place in the neighbourhood if current trends persist.

4.2. Lower NDG. Lower NDG, an interwar suburb in the city's west end, is mainly inhabited by an English-speaking and lower- to middle-income population, but like La Petite-Patrie, it was also a major area of settlement of Italian immigrants, the wave in this case beginning in the 1940s. In this case too, the Italian-origin population has halved in the decade 1996-2006 (6% to 3.2%). Unlike La Petite-Patrie, the main socioeconomic trend over the past decade or so has been one of stability, even stagnation relative to the metropolitan area, rather than increasing income levels (Table 2). However, a mega-hospital project, the new McGill University Health Centre (MUHC) campus, was planned over a decade ago and has been under construction since 2009 on a vast site immediately adjacent to a section of this neighbourhood, named after the Catholic parish of Saint-Raymond, which forms the core of our study area. This has already led to speculative construction of condominiums, although so far these have been low end of market. Significant revitalization of this working class neighbourhood is expected once the hospital is completed. Local community organizations have been highly proactive in warning about and trying to mitigate the potentially negative effects of gentrification on the area's low-income residents. Census data for 2006 (Table 2) show a neighbourhood whose older population is holding its own in absolute terms, but not in relative terms. A major change is that the absolute and

relative numbers of people belonging to a visible minority have risen considerably, unlike in La Petite-Patrie (Table 2), most of the increase being concentrated in the St-Raymond sector. As to two of the classic precursors of gentrification, the proportion of university degree holders increased faster than in the CMA as a whole but there was no relative increase in the weight of the 20-44 age group; thus, signs of incipient gentrification were less marked than in La Petite-Patrie.

5. Results

5.1. La Petite-Patrie. Before addressing the perception of changes and their assessment, it is important to describe the two main populations of older people residing in La Petite-Patrie: (1) the Italian population, homeowners who live in Little Italy, a sector within La Petite-Patrie (western sector of the neighbourhood); (2) the French-Canadians, who are mainly renters, residing near the centre and east of the neighbourhood. The Italians have a strong sense of attachment to Little Italy because this is the sector to which they immigrated, bought their first home, and raised their families (strong sense of autobiographical insideness). Several interviewees expressed their attachment to the area of Little Italy, comparing it to a village, or rather "the village". Their lives are organized around this relatively small geographic space, and they are able to run all their daily errands on foot. Almost all of the Italians had dense social networks within the neighbourhood. They also demonstrated strong attachment to shops and cafés they frequented on a regular basis as well as the local parish and associations. The public Jean-Talon market and parks also emerged as significant places that were part of their routine. Contrary to the Italians, the French-Canadians' attachment was more instrumental: as an 85-year-old female renter pointed out, "we appreciate the neighbourhood because everything is at your fingertips" [translation]. Yet, some French Canadian

participants expressed complex and deep-rooted attachment that went beyond the instrumental attachment to the neighbourhood. For example, the woman who was forced out of the neighbourhood because of a housing takeover continued to return frequently to shop in familiar stores. Other French Canadians felt attachment to La Petite-Patrie that went beyond having shops nearby; the attachment to their immediate environment became more evident as they expressed feeling threatened and uncomfortable with the arrival of new ethnic minorities.

For both populations, the perception of changes varied considerably among interviewees. Some participants perceived only very few changes, if any, while others perceived several. People living in social housing complexes or in older residents' apartment complexes generally perceived little change in the neighbourhood; many people living in these residences often only described the change in their individual residence. Moreover, the changes reported by participants focused on the immediate environs (one's neighbours, one's street, or at most a few surrounding streets). The most common change noticed was a perception of increasing ethnoracial diversity (which, as we saw in Table 2, is not supported by census data). Reactions to this varied from frank expressions of unease—a sense of strangeness in once-familiar public spaces which led some people not to frequent them any more—to discourses avowing tolerance and even a cosmopolitan mentality. For instance, one 79-year-old French-speaking woman stated, “*You have to go to McDonald's to see this. We don't feel at home, it's full of immigrants. I know. I don't understand how they let that many into the country! I just don't know*” [translation]. An 85-year-old French-Canadian woman said she felt “*invaded*,” “*It's too crowded now (St-Hubert Street), and you hear all different languages. We ask ourselves where we are. I don't like it. They are invading us! I am scared that in 10 years, what other languages are we going to hear? They are going to take everything from us ... all the businesses; it's them who are running them*” [translation]. French Canadian interviewees also reported that local churches were increasingly being “*taken over*” by the Haitian population. Some told us they attend church much less often because they feel out of place, “*I'm the only white face in the room*” [translation], an 82-year-old woman reported. In contrast, a man of Italian descent viewed this newfound diversity positively, “*it helps to know new people, other cultures, to reduce prejudice, because we are all alike!*” [translation].

Several interviewees reported that real estate values and rents had increased substantially in recent years. Several also pointed out the spread of condominiums, some referring to the transformation of a local church into quite luxurious condominiums. Despite the documented increase in the number of residents with university degrees, very few study participants noted the arrival of a younger, better educated and wealthier population to the neighbourhood, with the exception of one 76-year-old French-speaking woman who welcomes the arrival of more “*refined people*” [translation]. While some owners appreciated the increased value of their homes, others saw the recent developments as negative because they did not meet the needs of families

and low-income residents of the neighbourhood. An Italian-speaking owner noted that the neighbourhood has become prohibitively expensive, preventing members of his family to settle there.

As for the business changes, the positions were also very diverse. Some participants harshly critiqued the changes to two major commercial streets in the neighbourhood, notably St-Hubert Street where the variety of its stores had been lost and the new shops did not meet the needs of the older neighbourhood residents: “*All the stores we liked, they are all gone. They were all replaced by fabric stores, prom dresses, wedding boutiques ... “It is not at my age that I'll buy that!”* [translation] (71-year-old French-Canadian woman, renter). As for commercial shift of St-Lawrence Boulevard and the renovation of the Jean-Talon market, many appreciated the changes and the arrival of new businesses: “*there's a lot of progress in Little Italy, in shops, restaurants ... Many people are coming*” [translation] (71-year-old Italian man, homeowner). However, few say they regularly attend the new restaurants and cafés, preferring familiar places. Others lament the increased traffic in Little Italy and higher market prices that have forced them to do their shopping elsewhere. One 91-year-old Italian man (home owner) described his ambivalence about the changes: “*The Jean-Talon market used to be more traditional, now it has become very commercial, there are too many people, in the summer we can't go Fridays, Thursday evenings, and Saturday afternoon, there are just too many people! The market is working well, so for us; it is a good thing because the houses have doubled in value! To buy a home here, if I wanted to sell my house, they are going to pay!*” [translation].

A neighbourhood change that negatively affected a number of the French-Canadian residents was the disappearance of the Golden Age Clubs and bingos: “*Ah! It shocked me because it was the only fun we had. You know old people are not interested in going to bars to drink, I do not drink. That was the only place we had to go. So since it closed: “Stay home!” So we stay at home ... It's as if for older residents, we're just too old, they are just waiting for us to die!*” [translation] (71-year-old French-Canadian woman, renter). In recent years, three clubs catering to French-Canadians have closed their doors, while the Italian-speaking club continues to operate. According to two key informants, these closures are related to lack of leadership in the clubs, deficient financial support from the municipal borough, and to their declining popularity, especially as the aging population of the neighbourhood decreases. In this sense, the closure may be linked to the gentrification with the arrival of a younger and more educated population.

5.2. Lower NDG. The two main populations residing in Lower NDG are the Italian-Canadians, of whom those in our sample are all homeowners, and the English-speaking Canadians, of whom those we interviewed are both home owners and renters (Table 1). The scarcity of businesses in Lower NDG, especially in the St-Raymond sector, forces its residents to leave the neighbourhood regularly and frequently to meet most of their consumer, social, and in

some cases, spiritual needs. As such, their instrumental attachment is low, especially compared to the residents of La Petite-Patrie. Some residents expressed indifference toward their neighbourhood, as one 90-year-old English-speaking woman made clear when asked why she decided to move to the neighbourhood and stay for so many years: “*I don’t know, it’s a place to live, you have to live some place!*” However, some homeowners demonstrated a strong sense of attachment linked to their deep-rooted history with the neighbourhood. For example, one 74-year-old woman who bought the house she grew up in from her mother explained: “*It’s just home . . . My family they all stuck around, you know I got 4 children. And I have the 2 boys living here. I am very . . . My own son with his 2 kids down the street, it’s great, it’s great!*” However, compared to the Italian-origin residents, the social attachments among the English speaking Canadians were more family oriented around individual homes whereas the Italians met regularly to socialize at St-Raymond’s Parish and the bocce courts located behind St-Raymond’s Community Centre. (“Bocce” is a ball sport belonging to the boules sport family that is commonly played outdoors during the summer months among the Italian communities in Montréal.)

As in La Petite-Patrie, the most common change noticed in Lower NDG was the increase in ethnic minority populations (which in this case is more congruent with the census data—Table 2). Perceptions were also mixed, but several participants responded negatively toward the arrival of a medical transit house for Inuit people, as they felt the centre changed the image of the neighbourhood: “*I don’t know what they are going to do. I mean they (Inuit) are laying on churches . . . Churches lawns and . . . Well just yesterday, at the bus one was sitting in the door steps . . . I mean that’s not very nice when people pass on the bus and see it, it is not very nice for people living here either . . .*” (74-year-old English-speaking woman, homeowner). However, some residents, such as a 90-year-old English-speaking woman renter embraced the diversity: “*Now there is everything. There’s Hindus and Jewish, but everyone gets along well.*”

Some of the residents also reported feeling less secure in the neighbourhood: “*Put it this way, you ask me, if I feel at home on my street, yes. Ask me if I could go down to Saint-James, after 9 o’clock, no!*” (74-year-old English-speaking woman, homeowner). An 85-year-old English-speaking homeowner also mentioned that the neighbourhood is becoming less safe, that there have been a couple of recent shootings and a “person was beat up” at the top of her street.

Similar to La Petite-Patrie, there were also reports of lost institutions; for example, a 74-year-old English-speaking woman regrets the loss of the church in which she was an active member for over 40 years: “*I like my new church but I mean I loved my old church. That was a surprise, but I can worship anywhere. You know, it is not like I was married there, my father or mother . . . No they weren’t married there but . . . But all my kids were christened there . . ., you know, so I have a lot more attachment to that, I mean to that one.*” Despite this loss, there were no collective political movements to save this important institution. Some of the English-speaking interviewees expressed frustration and felt

they did not have a political voice, especially compared to the Italian population: “*It’s more difficult. First of all, the older residents’ voices are all Italian, who is going to give . . . I don’t think anyone really cares. I mean politicians pretend they do for five minutes to bet whatever bills they want passed; they make it look like they really care . . . Yes, but this is silly, but I think there is a place for giving people more of a say in life rather than just being consumers*” (73-year-old English-speaking woman, homeowner). Despite the generally reported deterioration of the neighbourhood, the arrival of the new community centre was unanimously viewed as a positive addition, as one 73-year-old woman owner pointed out: “*Oh! It is a beautiful place.*” Participants viewed the community centre as a new place to meet with their peers, “*At least now we have a place to go in the winter, where we can go for 2-3 hours during the evening.*” [translation] (70-year-old Italian woman, homeowner). Finally, interviewees expected important future changes with the construction of the new mega-hospital centre yet the opinions were mixed. Some consider the potential negative ramifications of the construction: “*I don’t know they’ve been talking about it for the past 10 years and nothing has happened yet. They’re talking about making it (main artery running through St-Raymond) a one way street . . . I can’t imagine that!*” (90-year-old English speaking woman, renter). While others viewed the new construction in a more positive light: “*I think because of the super hospital I think it has given people a boost, even though there’s been lots of complaints about what’s being done but the fact that at least there is some activity is making the place more . . . less of a forgotten area . . . Yes it is a place that will be convenient, and ah it will be fine. Rather before it was a place that you hardly knew it existed, so now it is coming into its own.*” (73-year-old English-speaking woman, homeowner).

6. Discussion

Through this study we obtained an improved understanding of how older residents who are aging in place experience neighbourhoods that are themselves undergoing change. The results show that even when older residents remain in place, they may experience feelings of strangeness, insecurity, and social exclusion.

The experiences of attachment to neighbourhood differed depending on the nature of the neighbourhood and the population at hand. Instrumental (or functional) attachment was not captured by Rowles’ threefold typology, yet it was the most widely reported among both the Italians and French Canadians in La Petite-Patrie. It is not surprising that there was no reported instrumental attachment in Lower NDG since the neighbourhood is lacking in local services, which forces the residents to leave the area to meet the majority of their daily needs. Commercial and institutional deficiency in Lower NDG not only prevented the residents from “living” the neighbourhood, it also prohibited them from establishing a routine with it (Rowles’ [38, 39] physical insideness). However, with the arrival of the new mega-hospital, residents may become more instrumentally attached, as some of the residents forecast that the construction will bring new businesses and services to their “forgotten” neighbourhood.

Two groups seem to stand out in both neighbourhoods, although we are cautious given the small number of participants: (1) the Italian homeowners, and (2) the English and French-speaking renters. First, neighbourhood attachment is recognized as being more prevalent for homeowners than it is for renters, the former's symbolic as well as material investment being greater due to their likelihood of moving less frequently than renters [45]. Second, compared to the Italians, the French- and English-speaking Canadian interviewees had a widely dispersed social network in the city, and/or had moved several times during their adult lives, thereby not establishing the same sense of social connectedness (social insideness) as the Italians. The Italians' description of the neighbourhood as a "village" effectively portrays their warm feelings of connectedness with neighbours and their surroundings and seems to be related to their stronger sense of autobiographical insideness, as they had built their lives in the neighbourhood. In Lower NDG, some of the English-speaking Canadians were homeowners, yet there was much less a sense of social connectedness and autobiographical insideness beyond their individual homes and their immediate families.

We have alluded to the fact that the older residents' perceived changes do not necessarily reflect the reality of the neighbourhood changes, especially in regards to the proportion of the visible minority population (principally in La Petite-Patrie). Yet the first, and sometimes the only, type of change noted in both neighbourhoods was in terms of visible signs of an increasing ethnoracial diversity and physical signs such as new condos, commercial revitalisation, and so forth. On the other hand, new younger and better-educated populations went virtually unnoticed. This relative invisibility of the arrival of this new population suggests that social class change is less dramatic than ethnic distinctions. This finding draws a parallel to Alba's [50] Mexican study, where changes related to gentrification were not perceived by interviewees besides home renovations. Negative comments relating to the perceived increase in ethnic minorities were more common than were positive ones. The French Canadians in La Petite-Patrie and the English-speaking participants in Lower NDG felt especially "invaded," that they no longer belonged or felt "at home" among the new faces on their once familiar landscape. The negative feelings of "strangeness" in a well-known environment provide evidence of indirect displacement and symbolic exclusion [29] resonating with Nord's [51] "politics of resentment" in which the London shopkeepers who were interviewed blamed multiculturalism and cultural diversity in the neighbourhood for inequalities and feeling powerless. On the other hand, the Italians did not report the same negative experience, which is likely to be related to their strong sense of social insideness to the neighbourhood.

Among the reported changes, the greatest effect on older residents was related to the closure of the Golden Age Clubs and churches as well as the revamping of a commercial street (niche market of bridal and evening wear) and a public market (higher market prices). However, an important distinction between the English- and French-speaking populations was that the English-speaking residents

of Lower NDG seemed less affected by changes, such as the closure of their Anglican church, because they were used to leaving the neighbourhood to meet their needs. In addition, an unexpected result was the implementation of a new community centre with activities catering to older people in Lower NDG, a deteriorating neighbourhood, whereas in La Petite-Patrie, a neighbourhood undergoing gentrification, we see the closure of important institutions for older adults. This surprising finding is at odds with the viewpoint of Bowling and Stratford (2007) [52] who suggest that increasing the affluence of an area may improve the social and physical functioning of older people who are aging in place. This was not the case in La Petite-Patrie, where the closure of French-Canadian Golden Age Clubs led to a form of "house arrest" for some of the participants. Yet, in Lower NDG, the English-speaking Canadians reported fear of crime, which prevented them from going out at night. As noted by Anne-Marie Séguin et al. [53], when one is confined to the home it becomes a place of isolation and invisibility. Feelings of insecurity and the disappearance of familiar institutions provided evidence of Billette and Lavoie's [29] dimension of territorial exclusion. Conversely, in both neighbourhoods, the Italians had managed to maintain their social and cultural institutions. For instance, at present, the Italian Parish in La Petite-Patrie has many members who attend very regularly, and a number of activities continue to be organized around the church. Similarly, the Italian Golden Age clubs of this community continue to operate, contrary to the French-Canadian clubs. A key informant even spoke of the older Italians wanting to open a residence catering specifically to Italian seniors in Little Italy. Similarly, in Lower NDG, the older Italians continued to meet regularly at St-Raymond's Church and the bocce courts located behind St-Raymond's Community Centre.

For a number of reasons, the residents of Italian descent in both neighbourhoods viewed the neighbourhood changes with more serenity and comfort than the French- and English-speaking Canadian residents. Similar to Pashup-Graham [28] whose Chicago-based study unveiled some of the positive consequences of gentrification, the Italians viewed the revitalization with enthusiasm; they recognized that the neighbourhood was becoming more attractive and that the value of their homes was increasing. While the Italians were mostly homeowners, giving them some protection against the gentrification of the neighbourhood, the French Canadians were all renters. It is thus not surprising that the renters we met, be they French or English-speaking, were at the same time less attached to their neighbourhood and possibly more vulnerable to perceived and objective local changes generating experiences of social exclusion. For instance, the French- and English-speaking Canadians were experiencing forms of symbolic exclusion, as was pointed out by two key informants who believed that these populations were no longer seen or heard, rendering them invisible. Similar to Martin [23] who looks at political displacement, the absence of the voices of this population in politics and decision making also suggests a form of sociopolitical exclusion. The visibility and political influence of the Italians were obvious to some of the other interviewees, which may

have reinforced feelings of exclusion among the French- and English-speaking populations. This finding is supported by Phillipson [14] who writes, “variations in community attachments now illustrate significant inequalities within the older population: most notably between those able to make conscious decisions about where and with whom to live, and those who feel marginalised and alienated by changes in the communities in which they have “aged in place” (page 336). Finally, unlike the French- and English-speaking communities, the Italians had managed to maintain their cultural and social institutions. The reasons for this preservation are complex, and we are cautious given the small sample size; it appears that their strong sense of physical, social, and autobiographical insideness led to greater visibility, political power, and control over changes, which in turn protected them from some dynamics of social exclusion.

The first expected impact of gentrification is often financial [54]. An unexpected finding was that almost no respondents experienced economic exclusion. This appears to be related to the fact that La Petite-Patrie is undergoing incomplete gentrification [55]; that the neighbourhood is maintaining a certain social mix that is manifested by the heterogeneity of businesses, the cost of housing, and social status of the population. A second potentially protective element is that Québec has a system of rent regulation. The situation could be very different in other cities that do not have these protective measures in place; thus there is scope for further research.

7. Conclusion

The majority of environmental gerontology research has focused on how to provide security and strengthen an older person’s sense of self while they age in place. There is a call for further research that considers how neighbourhood change affects older residents who age in place. This study goes beyond economic impacts of neighbourhood change and considers the importance of social, cultural, and political consequences that may affect people’s quality of life. Our observations also support the relevance of examining the possible role of gentrification in the dynamics of social exclusion of older people who are living in a changing working class neighbourhood and, at the same time, have little control over local institutions and organizations that are essential to meet their needs. In addition, this study reinforces the importance of considering the heterogeneity of the older adult population; inequalities and social differences still exist, even within golden age cohorts. To this end, Manzo [56], citing Hummon [56], recalled that the rootedness of some members of the community involves the removal and exclusion of other members. Finally, our findings demonstrate the crucial role that social spaces play in order to maintain or develop social links, increase visibility and consequently feelings of inclusion. There is a need to maintain these social spaces for older residents, especially in changing environments, to ensure that older people have a space to be seen and heard.

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Research Article

Older Adults with Hoarding Behaviour Aging in Place: Looking to a Collaborative Community-Based Planning Approach for Solutions

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This paper reports on and synthesizes new research that examines how a collaborative community response can promote successful aging in place for older adults with hoarding behaviour. Through interviews with older adults with hoarding behaviour, who used a particular community support and a focus group interview with members of the community collaborative that directed supports for this population, our findings suggest that there were valuable outcomes for both groups. These older adults with hoarding behaviour were able to remain in their own homes, their safety was enhanced, their sense of isolation was minimized, empowerment was fostered, and they gained valuable insight into their behaviour. The members of the community collaborative were able to access the expertise of other professionals, maximize their own expertise, and they generated an enhanced understanding of the experience of older adults living with hoarding behaviour in Edmonton. This study is a significant addition to the much too sparse literature about the community planning needs of older adults with hoarding behaviour. It offers knowledge that is integral to theories and principles of better aging in place but attempts to translate this into practice.

1. Introduction

Older adults with hoarding behaviour are often at a high risk of being homeless making aging in place extremely complex. This paper reports on a study that examines the value of a community-based planning approach that responds to the needs of this population, a population that is both increasing in number and that is very seldom studied [1]. It synthesizes new research about the complexities associated with remaining in one's own home when he/she is over 55 and has compulsive hoarding behaviour. And it examines how a collaborative community response promotes successful aging in place for this population. Not only are community-based services necessary to better understand because they are central to all health sectors [2], but also current research surrounding those with hoarding behaviour is mostly focussed on methods addressing individual-level

behavioural characteristics of hoarding through cognitive behavioural therapy (cf., the extensive work of Frost and Steketee). Missing are descriptions of community-based planning approaches for health and social service sectors working hard to make aging in place a possibility.

For older individuals with hoarding behaviour, aging in place is complex because hoarding behaviour is multifaceted; it touches on social, environmental, familial, and personal issues [3]. Aging in place is also not simple for those with hoarding behavior because they want to remain living in their own homes, neighbourhoods and communities which seem to require that a collection of agencies, often representing different sectors, understand their needs in order to help them stay in the community and age in place. In this paper, aging in place refers to an ideal where people can age in the familiarity of their homes, neighbourhoods, and communities where their quality of life is maximized by

the availability and accessibility of supports and services that respond to their needs and capacities [4, 5]. Aging in place, in addition, is about belonging to a community that supports one's many needs, for example, physically, socially, mentally, environmentally, and so forth [6]. To understand the varying aspects of aging in place in late life, older individuals with hoarding behaviour need to be further understood so their aging journey is successful; collaborative approaches by community support agencies can help to make that possible.

In our case, social and health related organizations from different sectors, that in some way supported people with hoarding behaviour in Edmonton, AB, Canada, were brought together in 2007 through the leadership of the social worker of a seniors support agency called SAGE (Seniors Association of Greater Edmonton). After having visited a number of individuals with hoarding behaviour (age 55+) in her professional role, she noticed, as did those members of the imminent community collaborative, that those with hoarding behaviour were at a high risk for being evicted from their homes, and they experienced shame associated with their hoarding resulting in isolation, as well as depression; they were at risk of falling in their own homes, and generally, they were living in unsanitary conditions. To approach this highly vulnerable population, to respond to some of their needs, especially to prevent their potential eviction, a concerted effort by a broad representation of social, health, and other agencies was necessary. The collaborative met together regularly (e.g., once every 2 months over the years and as of June 2011, it continues to meet) to continually plan for and improve the support of older adults with hoarding behaviour in the Edmonton area.

Although little is still known about the effects of one's neighbourhood on the mental health of older adults, positive mental health in later life may be influenced by the way in which older people feel about their neighbourhood [7]. It is fair to conclude, therefore, that for older adults with hoarding behaviour, place matters and the role of place as locality is key when making meaning at both the individual and the collective levels. In particular, local place is an important factor in identity, in one's sense of community, and attachment; this is crucial to the determinants of attachment, satisfaction, and behaviour [8]. Also important is place and the person-place relationship are very much grounded in a context of fear over loss of place [9] and the obliteration of locality [10]. Aging and compulsive hoarding behaviour need to be examined in concert with one another.

As our aging population rapidly increases, the number of older adults with hoarding behaviour will also quickly increase. Although hoarding behaviour usually begins in early adolescents, its severity increases with age [11]. Results from the Hopkins Epidemiology of Personality Disorder Study found that the odds of hoarding were over two times as great in the oldest compared with the youngest age group [12], and in a study of hoarding-related complaints to public health departments in Massachusetts, 40% of individuals that hoarded were involved with elder service agencies [13].

Referring to Frost and Hartl [14] when defining hoarding behaviour, there are key characteristics: the acquisition of and failure to discard a large number of possessions that

seem to be of little use or limited value; cluttered living spaces that cannot be used as intended; significant distress and/or impairment associated with the clutter. Hoarded possessions clutter living spaces until rooms are difficult or impossible to use for their designed purpose, causing significant stress to the individuals themselves. Possessions may be purchased through compulsive buying [15] and/or through acquiring things like newspapers or discarded items from dumpsters [16]. Some individuals may even steal new possessions. After acquiring possessions, discarding these items is extremely difficult [17]. In serious instances, household clutter may interfere with and prevent daily activities, like food preparation, moving freely in one's home, and using the bathroom [11, 17]. And as clutter increases, falling, fire, sanitation issues, depression, and isolation are possible, creating significant risk for a number of outcomes but especially eviction and thus homelessness [18].

Community collaboration is one way to respond to social and health needs of a population. In fact, genuine collaborate is said to be the very thing that successfully reforms health systems [14]. Although there are many ways to define collaboration, most definitions emphasize the importance of shared responsibility and a team approach [20], and using a collaborative approach can significantly increase the available pool of resources from which team members can draw [21]. A response to the multiple challenges of older adults with hoarding behaviour requires a comprehensive and far-reaching approach, more than one single agency can provide alone [22, 23]. Philosophically, collaboration is rooted in systems theory which says that entities in a system are dependent on one another [24] and ecological theory in particular proposes that causes and solutions of health and/or social problems are beyond the individual and are associated with such determinants as the health and social services that we receive [25]. Service recipients can benefit from a collaborative approach to the provision of community health services as can the agencies participating in the collaborative [26–28]. Using a collective made up of representative agencies to support this vulnerable population creates potential for an approach that builds on the strengths of all those involved.

2. Methods

Between January 2007 and January 2010, approximately 75 older adults (ages 55+) with hoarding behaviour in Edmonton, AB, Canada, were provided with community supports to prevent them from being evicted from their homes [29]. The Seniors Association of Greater Edmonton (SAGE) offers support through a program referred to as *This Full House*. And *This Full House* is a direct outcome of the work of the community collaborative. The aim of *This Full House* for older individuals with hoarding behaviour is to prevent eviction from their home, improve their health and well-being, maintain positive social contacts, and contribute to the building of a healthy community [29]. As the population of potential participants with hoarding behaviour in Edmonton is not particularly large, a small-n approach was used in an attempt to create heuristic generalizations

which Tsoukas [30] defines as opportunities to refine analytic understanding and to make more incisive distinctions than were previously possible. Small-*n* studies are not designed to support or refute a theory, but rather, to further refine it. As such, the purpose of this study is to further examine the role of a collaborative planning approach in a community setting when seeking to help those over 55 years with issues relevant to having compulsive hoarding behaviour and wanting to age well in one's community.

To further understand the value of collaboration and, in particular, its role and value in this community support, interviews and a focus group were conducted with seniors with hoarding issues involved with *This Full House* and with the community collaborative. All interviews were semi-structured and conducted by a third party researcher (i.e., Research Assistant). Ethics approval for this research was received from the University of Alberta, Research Ethics Board.

2.1. Interviews with Individuals with Hoarding Behaviour. Individual interviews were conducted with five ($N = 5$) individuals with hoarding behaviour involved with *This Full House*, all of whom were over the age of 55. The semistructured, face to face interviews took place at a location expressed as being most comfortable to the interviewee, for example, at their homes, at a university office, at a nearby coffee shop. These study participants were first contacted by the social worker from SAGE who directs *This Full House*. The individuals with hoarding behaviour had either referred themselves to *This Full House* or had been referred to it by one of their health care practitioners or family members. At an appointment with the individuals, the social worker informed them about the study asking if they might be interested in being interviewed by a researcher about their experience with *This Full House*. If they agreed (which all five did), she gave them a one-page written description of the study. She then went through the summary of the study ensuring they understood what was being requested from them. With their agreement, their telephone numbers were provided to the researcher (i.e., Research Assistant) who contacted them and established a location and time to meet for the interview. The aim of the one-hour interviews was to gather information regarding their experience with *This Full House*. In particular, the interview was used to understand their perceptions of the impact of or value of their association with *This Full House*, that is, the aspects of the program they benefitted from most.

2.2. Focus Group with the Community Collaborative Members. A community collaborative made up of social and health related agency representatives providing insights into the ongoing development of *This Full House* was formed. The focus group interview included ten members ($N = 10$) (of the possible 11 members in total) and was conducted in a face-to-face manner for approximately 1.5 hours. Members of this collaborative represented a number of expert groups: social workers, home care nurses, geriatric neuropsychologists, geriatric nurses, fire and safety investigators, public

health practitioners, and environmental health and safety officers. The focus group questions centered on the nature of the working relationship between and amongst the members and their observations about the value and impact their work may have had on the service users, that is, those with hoarding behaviour. The questions guiding the semistructured interview were generated from key themes highlighted in the literature (i.e., health services, collaboration, community support, etc.) that aligned with the purpose of the study.

3. Results

Use of a grounded theory framework was quite valuable for our data analysis. Grounded theory means that the data analysis essentially, is "grounded" in the data [31]. Therefore, the concepts and themes we describe in our results have evolved from and are embedded in the data collected and have been mined through a process of conceptual ordering. Grounded theories are said to provide further insight, to enhance understanding, and to be used as a guide to inform action (i.e., acting on the results). As Strauss and Corbin [31] describe in more detail, our interview data, in the form of pages of the exact words from the interview, was organized into categories that were not predetermined but that evolved after reading and rereading this data many times. And that, mainly described ideas and offered explanations from interviewees that had commonalities to each other. The themes described here are those that were mentioned frequently and carried the same meaning.

Because our aim in this study was to further our understanding of how older adults with hoarding behaviour were supported by a particular community-based planning approach, grounded theory provided the most effective means of organizing, reducing, and understanding the data. Suggested below is a picture that describes how the work of the community collaborative, because of its high level of collaboration, resulted in many important benefits for older people with hoarding behaviour that align well with and facilitate the goals and ideals associated with an aging in place model. The picture also describes how the community collaborative members valued their experience on the team.

3.1. The Work of the Community Collaborative Benefitted People with Hoarding Behaviour. As a result of this group working together to respond to the needs of older adults with hoarding behaviour, several themes evolved from the data demonstrating direct benefits for these individuals: being able to remain in their own homes; reducing their potential for harm, and minimizing their isolation all which allowed them to experience a feeling of empowerment which also helped them to generate insight into issues surrounding their hoarding behaviour.

3.1.1. Remaining in Own Home. There are considerable challenges associated with aging in one place for older individuals with hoarding behaviour. They can be at significant risk of being evicted from their homes and their behaviour can be a major public health concern leading to eviction as

a result of violating building, fire, or property maintenance codes. It may not be until a particular emergency occurs (i.e., water leakage, fire, and pest infestation) that a landlord is notified [32]. One focus group member describes their role, as a member of the community collaborative, in minimizing evictions for this population:

“Our legislation says that we do have the right to go into any public or private place if we believe there may be a public health nuisance... and if that means we have to order their suite cleaned out, we’ll do it. Um, because you can’t get control of bedbugs and cockroaches unless you treat all the suites and if somebody’s hoarding, you can’t get rid of them... so, so they have to clean up.”

The five interviewees in this study were all in a situation where eviction from their homes was a potential, but they were able to remain at home as a result of a community-based approach that addressed some of their needs. Prior to the existence of this community collective, one focus group member describes how the health inspector had to play all roles and visit clients once a week and “nag people into cleaning up, which was mostly unsuccessful.” For example, when there is a potential home eviction for individuals with hoarding behaviour, the social worker and a public health worker, together with the client and other members of the collaborative, that is, where necessary such as a fire and safety representative, provide input into the problem-solving process. A professional organizer usually assists with the practical aspects associated with cleaning up including heavy lifting, removing garbage, and reorganizing resulting in “[these clients being able to] stay living at home without being on the street and [being] homeless.” Being able to age in one’s own home, one’s neighbourhood, and community fosters independence significantly impacts a more positive relationship in the person-place relationship [33].

The five people with hoarding behaviour that we interviewed spoke about the value of being able to remain living in their own homes. One person found it motivating to have someone help him/her to clean up his/her apartment, “it’s the motivation of having someone there plus... the helper doing the heavy lifting and heavy carrying... making... 76 thousand trips to the garbage bin... its stressful but helpful [and] I certainly would not have been able to hire a company on my own [...] if the program had not been in effect [and] I would be in deep do-do with Capital Health.” For another individual, what helped him remain in his own home was having the home care worker put him in touch with the social worker and the cleaning person who helped him find ways to deal with issues of parting with his stuff. And for this gentleman, the social worker supported him by suggesting options: “she made life more convenient for me by offering me options.” And for another person, the social worker and the cleaner reminded her that the condition of her house, the bugs, the mouse droppings, the make up from years ago, the shiny covered magazines all over, and the infestation that she had, was not her fault and she could probably face organizing and cleaning it with encouragement and the help of a plan.

3.1.2. Reducing Harm and Promoting Safety. Hoarding behaviour creates a significant safety risk for the individual him/her self and for the community [32]. Harm reduction is a core principle that is essential to address the needs of those with compulsive hoarding behaviour because promoting safety is foremost [13]. In this case, focusing on harm reduction by the community collective ensured that safety was embedded within all the actions, initiatives, and supports they provided. One focus group member talks about the value of taking on this strategic focus: “We subsequently learned the value of focusing on a harm reduction approach wherein we address issues of harm first so that the person [with hoarding behaviour], at least, will be safe. Even though they may be living with a significant amount of stuff every day of their lives, but at least they are safe.” A harm reduction philosophy considers behaviour change to be incremental and assumes that people will maintain their behaviour change when they have decision-making power to influence their goals and put them into action [34].

This focus on safety and reducing harm or the potential for harm helped the individuals with hoarding behaviour buy into the larger process at hand, that is, to contribute to the building of healthy neighbourhoods, supporting their well-being, and helping them stay in their homes as long as possible. Instead of suddenly or immediately removing the person from a potentially unsafe environment or situation, the aim instead is first to reduce the potential for harm and create a safe place to live. In the case of these five individuals, it meant such things as: hiring a person to help them remove and reorganize their excessive items, getting help to fumigate their apartments, openly talking about their hoarding situation to help them reflect upon it, receiving nonjudgemental support, and establishing a plan to minimize household items. One interviewee describes the value of setting goals and generating a plan, “we set a plan and the social worker would come back and generally we would accomplish that goal whatever it was.” It also meant helping the person at risk of potential eviction, for example, to respond to requests made by the Public Health Inspector. One person with hoarding behaviour describes the role of this service (i.e., *This Full House*): “they sort of mediate [between varying agencies] and rub off the sharp corners.” Reducing harm by promoting safety enables an aging in place philosophy and model as both can facilitate positive and long-term aging in one location.

3.1.3. Minimizing Loneliness. The community collaborative, used in this study as a planning approach helped to address the problem of isolation for these older adults. Several of the representative organizations of the community collaborative, that is, a social worker, public health nurse, geriatric nurse, and so forth, offer home visitation to many of their clients and observe their living environment. As observed by one community collaborative member, “a lot of these seniors are very lonely, very isolated, and so the fact that they have someone that’s coming to their home often, helps.” Another member talked about the impact of the support group (which is provided for people with hoarding behaviour on a monthly basis as part of *This Full House* services) on

minimizing their sense of loneliness and connecting with people that have similar experiences: “[there is] value of that coming together, meeting with other people and seeing and hearing that you’re not alone.” Two interviewees with hoarding behaviour confirmed this same sentiment, about the importance of feeling connected to a group: “the group has helped me” and “[I realized] you are not the odd one out.” As a result of not feeling alone and part of a group, interviewees with hoarding behaviour said that they felt empowered.

3.1.4. Fostering Empowerment. Empowerment can be an outcome of collaborative relationships; it offers a catalyst for new community programs and other supports, changes in policies, and advancing health practices [35, 36]. The members of the community collaborative intentionally aimed to facilitate empowerment using it as a principle to guide their work that addressed the needs of older individuals with hoarding behaviour in the greater Edmonton area. During the focus group interview, one member describes how empowerment as a guiding principle was translated into action benefitting a particular individual with hoarding behaviour:

“We [the community collaborative] have entertained some really creative approaches in terms of dealing with management [i.e., housing manager] and having the client lead those interventions [...] as opposed to, we [the service providers] meet[ing] with management, then... meet[ing] with the client... we really include the client in those interventions, so that the client really is aware of everyone that’s involved, what’s being discussed and then they are really empowered to be part of the action plan.”

When individuals with hoarding behaviour are more involved in directing their own support, they may experience greater control in such decision making which can lead to empowerment [13]. As observed by another community collaborative member, “[empowerment provides] a sense of control in a situation that they may feel a lack of control.”

3.1.5. Communicating Insight into Their Hoarding Behaviour. The most successful reported treatment for those with compulsive hoarding behaviour is the use of behavioural treatment, in other words, a cognitive behavioural model [37]. To be motivated to discard their possessions, insight into their hoarding behaviour is significant [14, 38]. Members of the community collaborative said that individuals with hoarding behaviour seemed to gain insight into their behaviour as a result of the support provided by this collaborative. This observation was expressed during the focus group interview by the social worker:

“... the insights that come out as a part of the intervention, as you go along, then they [clients with hoarding behaviour] start to reveal some insight as to “how did I ever get to this place? and, “I can’t believe this happened to me” and “I can’t believe that I’m actually, I’m making some decisions now that I was not able to before.””

During an individual interview, one individual with hoarding behaviour reflected on the changes in her own behaviour of accumulating things: “I would still be walking down one little path between the bathroom, bedroom and one side of the kitchen and that would have been it.” Another interviewee with hoarding behavior expresses insight into her hoarding behavior: “they [the social worker] finally were able to get me to accept... this condition... that it probably was not my fault and that I could probably face it... it’s been a great support... eye opening.” And another person said something similar: “when I think how far I came from the first day... it [my behavior] improved.” She also said “I need to continue both thinking about and maybe following up [...] with counseling [...] is there an answer why I have become a person who allows clutter around myself [...]?” In the one-on-one interviews, individuals reported an improved feeling of independence and a sense of empowerment. This occurred because the collaborative team joined forces, they were united by a common goal of supporting, to the best of their ability, the needs of this population who they noticed to be struggling more and more and who they were being called upon more frequently to try to assist.

3.2. Participating in the Community Collaborative Benefitted the Group Members, Individually and Collectively. On individual and collective levels, the members of the community collaborative experienced three significant benefits as a consequence of participating in this group. For example, members of the collaborative were able to access the expertise of other professionals, they maximized the use of their own skills and knowledge and significantly enhanced their understanding of hoarding behaviour.

3.2.1. Accessing Expertise from the Other Group Members. Working on the collaborative team allowed the individual members an opportunity to access a broader range of skills and knowledge than those who were found solely in their own area of expertise or their own organization. In one instance, a professional social worker described how she could now present the risks associated with hoarding behaviour more objectively to a client with greater confidence as she could make reference to and more easily call on the authoritative role of the local fire department. Because the firefighter and social worker were both members of the collaborative, a close working partnership was facilitated. This benefit was expressed in this way: “when I mention to her [the client with compulsive hoarding behavior] the possibility of having someone from [the fire department] come and just do an assessment to let her know what her risk level is [i.e., of eviction from her home], she was suddenly open to that.” As a result of working collaboratively, members also got to know more about the professional resources available to them in the community through their ongoing communication together. As one health professional of the community collaborative said: “it is a professional benefit to see and use the expertise around this table for the benefit of the individual clients.”

Evaluating collaborative planning practices must consider not just the purpose of the collaboration but the value

of its relational interactions [28]. For example, asking how social relations are changed can reveal how certain conditions are impacted for the group. Access to new areas of expertise is one descriptor of the quality of social relations. The sharing of expertise between and amongst the members was said to directly benefit the older people with hoarding behaviour using the services of *This Full House*. In the words of one member of the community collaborative, “a benefit of the collaborative process was working with everybody, to partner, to ensure that we’re getting our clients the best support.”

3.2.2. Maximizing their Own Expertise. Participating in this group allowed team members to maximize the use of their own expertise. One member, a public health inspector, recounted a time when such a collaborative approach was not used to support older adults with hoarding behaviour illustrating the tremendous limitations of working in isolation:

“Before... [the community collaborative existed] it was [up to]... the health inspector to try and play all roles and just sort of go and visit once a week and try and nag people into cleaning up. Which was mostly unsuccessful and wasn’t really our job. I mean we are not social workers, we’re not mental health workers, we are public health inspectors.”

Functioning alone, the health inspector had to operate as the only contact for this client group. Working in isolation took away time from the job he/she was actually trained and hired to do forcing them to work beyond their professional scope of practice. As further evidence of the value of being able to maximize one’s own expertise, the professional organizer, who provides hands-on assistance with the cleanup of client homes, can now maximize her cleaning and organizational skills while directing clients’ emotional issues to a trained professional. As described by the social worker during the focus group interview: “A big portion of her [the professional organizer’s] time was addressing the [clients] emotional issues. So we’ve now learned that when those issues come up, it’s a direct link back to me.”

3.2.3. Enhancing Their Knowledge of Hoarding Behaviour. Members of the community collaborative described how their partnering with one another as professionals helped to enhance their knowledge and understanding of compulsive hoarding behaviour. Gaining new knowledge and a more “enlightened understanding” of compulsive hoarding behaviour was said to be the result of participating in this ongoing process. One member of the collaborative described the value of the increase of his knowledge stating “another professional benefit [of being a member of the community collaborative] is deepening my personal understanding of what hoarding is and what the dynamics are. Certainly, it’s helped me in recognizing that it’s multi-faceted.” Group members said they were then able to take their learning back to their representative organizations: “I think working with [the collaborative] has really helped to educate me and hopefully the rest of [name of organization].” Successful

aging in place requires that support by community-based organizations exists that it is available and accessible and responsive to a variety of their needs; therefore, knowledge about aging and its long list of associated issues, such as compulsive hoarding behaviour, is imperative.

4. Discussion

The aim of our discussion is to explain several matters that underpin the major themes of our results. Explaining why such themes evolved and their relationship to the broader phenomenon being studied is what Strauss and Corbin refer to as the process of theorizing [31]. At the heart of this study is community-based planning as a phenomenon of which a number of related concepts are embedded: aging in place, social support, collaboration, vulnerable populations, and community services. Overall, our research attempted to discover how a collaborative approach to planning for and addressing the needs of older adults with hoarding behaviour, living in the community, provided value. For these vulnerable adults living in Edmonton, Alberta, Canada, a collaborative planning approach that involved multiple agencies (representing varying sectors) that worked continuously to improve their quality of life made a difference. And, the members of this community collaborative also benefitted. From this approach they were able to access the professional expertise of the other group members, maximize the use of their own skills and knowledge, overall, giving them an opportunity to generate new insights into hoarding behaviour which they described as helping them provide the best possible care and support to this population. It is feasible; therefore, to use such results to inform the many ways to age in place more successfully in late life.

Currently there is no systemic, long-term process to support older people living in the community that have compulsive hoarding behavior. Nor in Canada, is there an overall strategy to plan for our aging population, therefore aging in place, at a national, political scale, is not yet a priority. But, because people with this behavior will increase in numbers, and the complexities associated with their need to live safely in their own communities, a national strategy must also address their specific and unique needs. As emphasized by The Canadian Health Services Research Foundation [39], our study also finds a need for enhanced integration, cooperation, and coordination at the system and at the service delivery levels. That is, integration and collaboration between health and social services, between ranges of sectors, between disciplines of front line workers, and between government ministries. Collaboration and integration need to be part of the foundation upon which aging in one’s own home and community can be realized. In addition, our study supports the findings of Keonig et al. [3] who found that when having to facilitate ethical dilemmas for this population, older adults with hoarding behavior benefit from the use of teams whose members have a variety of disciplines.

Well evidenced in the health services planning literature, applied to an aging population, is the need for improved collaboration, both at a principle and a practice-based

level [35]. Our study also confirms and emphasizes this important need. Not only do our findings align with the literature but it provides further insight into the challenges associated with older individuals that want and deserve to remain in their own homes. Our particular case is specific to older individuals that have hoarding behaviour that were supported through the efforts of a community collaborative planning approach. Our study adds to the current aging in place literature and extends it. The current literature supports collaboration and integration at varying levels of the health and social support system. But studies that examine community planning approaches grounded in collaboration are uncommon. This population will increase in numbers over time and they deserve to remain in their own communities with the support of surrounding agencies and organizations that work together to best support older individuals with hoarding behaviour to age well in their own homes.

5. Conclusions

At the heart of several concepts and themes arising from interviews with older people with compulsive hoarding behavior and members of a community collaborative working to support this population is an approach founded on collaboration between and amongst service providers. Results demonstrated that when a highly collaborative approach to planning is used, there were quite direct benefits for older adults with hoarding behavior and, at the same time, there were benefits for the members of the community collaborative. This approach to planning for the health and social needs of this population resulted in people with hoarding behavior being able to remain in their own homes when eviction was a potential, enhancing their safety, helping to minimize their isolation, and creating opportunities to increase control in their own decision making. The members of the community collaborative could now access the expertise of other professionals, maximize their own expertise, and they generated new insight and understanding of the experience of older adults living with hoarding behaviour in Edmonton. Our study needs to be viewed within certain boundaries. Although our data conveys that this approach to planning has quite positive outcomes, our data is short term and situational. Our use of a single, one-time only interview method only allows us to draw insights and observations about that moment in time and not over an extended trajectory. As well, our study is grounded in five interviews with older adults with compulsive hoarding behavior. And although a collaborative approach to addressing the needs of older people with hoarding behaviour conveyed comprehensive benefits, collaboration as a planning approach is rarely the complete answer or solution to people's social and health needs. Health Integrated Delivery systems, for example, are far more comprehensive but do view collaborative planning as a core principle [2]. Viewed in this light, aging in place may not always be possible, but it must be realized that community-level social and health related supports maximize the quality of later life while aging at home [5]. And further building on

that is the need for a well-coordinated model of care [5, 35] where supports are comprehensive, easily accessible, and well connected [5].

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Research Article

Cost Effectiveness of a Home-Based Intervention That Helps Functionally Vulnerable Older Adults Age in Place at Home

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Evaluating cost effectiveness of interventions for aging in place is essential for adoption in service settings. We present the cost effectiveness of Advancing Better Living for Elders (ABLE), previously shown in a randomized trial to reduce functional difficulties and mortality in 319 community-dwelling elders. ABLE involved occupational and physical therapy sessions and home modifications to address client-identified functional difficulties, performance goals, and home safety. Incremental cost-effectiveness ratio (ICER), expressed as additional cost to bring about one additional year of life, was calculated. Two models were then developed to account for potential cost differences in implementing ABLE. Probabilistic sensitivity analyses were conducted to account for variations in model parameters. By two years, there were 30 deaths (9: ABLE; 21: control). Additional costs for 1 additional year of life was \$13,179 for Model 1 and \$14,800 for Model 2. Investment in ABLE may be worthwhile depending on society's willingness to pay.

1. Introduction

The primary health problems confronting older adults are chronic and can affect their ability to carry out everyday self-care [1]. Functional difficulties significantly compromise quality of life and are associated with increased frailty, depression, nursing home placement, and mortality [2, 3]. Numerous interventions have been tested in randomized trials that may help older adults with late-life disability age in place at home [4, 5]. Nevertheless, research shows that functionally vulnerable elders continue to receive inadequate care [6–9]. To reverse this situation and enhance wide-scale adoption and implementation of proven programs in service settings, economic evaluations of promising interventions must be conducted [10, 11].

Only a few home-based interventions targeting older adults with late-life disability have been evaluated for cost effectiveness with studies demonstrating cost savings. However, most of these studies have involved European

programs or preventive approaches not specifically designed to improve function or reduce mortality in at-risk vulnerable older adults living at home in the USA [12–14].

One promising home intervention tested in the USA is Advancing Better Living for Elders (ABLE) [15, 16]. ABLE was previously tested in a two-group randomized parallel trial with 319 older adults who had difficulties with instrumental or daily activities of living. ABLE was designed to address client-identified functional difficulties, performance challenges at home, and home safety concerns. Compared to a no-treatment control group, ABLE was shown to reduce functional difficulties and enhance home safety and self-efficacy to manage daily functional challenges at 6 and 12 months. Moreover, ABLE reduced mortality at 12 and 24 months from study entry [15–18].

Given ABLE's promising outcomes and to extend an understanding of the benefits of this intervention, we conducted an economic analysis post hoc. The purpose of this study is to estimate the cost effectiveness of implementing

ABLE from the perspective of a homecare agency. Only costs associated with the implementation of ABLE were considered and two cost scenarios were developed to account for potential cost differences in implementing ABLE. These analyses used an incremental cost-effectiveness ratio (ICER) with the primary outcome measure of life years saved (LYS) over two years.

2. Methods

2.1. Study Design and Sample. The original ABLE trial was conducted between 2000 and 2003 with survivorship followed out to December 2005. As previously reported [15], trial participants were 70 years or older, cognitively intact, and living at home with functional difficulties. Participants were recruited through service agencies and media announcements. Of the 319 participants enrolled, 159 were randomized to ABLE and 160 to a no-treatment (usual care) control group. For this study, baseline interview data was used to characterize the sample. Data from the National Death Index (NDI) records were used to determine length of time of survivorship up to December 31, 2005.

2.2. Intervention. ABLE participants received five occupational therapy (OT) contacts (four 1.5-hour visits and one brief telephone contact) and one 1.5-hour physical therapy (PT) home visit over the first six months. OTs identified and prioritized functional difficulties, and provided strategies to modify the environment, enhance safety, and minimize performance difficulties. OTs identified home modification needs and, with client approval, coordinated product ordering, delivery, and implementation through the Housing Department of the Philadelphia Corporation for Aging (the region's area agency on aging). PTs provided balance and muscle strengthening exercises, fall recovery techniques, and referral for additional therapy if necessary. In the following six months (maintenance phase), participants received three brief OT telephone calls to reinforce strategy use. A final OT home visit provided closure.

Control group participants did not receive intervention contact. At study completion (12-month interview), participants received a home safety booklet free to the public.

2.3. Cost-Effectiveness Model. A decision analytic model was constructed for the cost-effectiveness analyses using TreeAge Pro 2009 statistical software. Two models were constructed to account for variation in cost estimates. Model 1 (base case) reports on estimated costs of delivering ABLE in a home care agency. Model 2 (base case + 10%) accounts for a potential variation in the cost of delivering ABLE in a real world setting.

2.4. Cost. Costs were calculated based on recommendations of the US Public Health Service Panel on Cost-Effectiveness and major peer-reviewed journals [1, 19–23]. All costs inputs are reported in Table 2; costs were captured in 2003 dollars to reflect when the original data was collected and then adjusted to 2010 dollars. Costs of the intervention reflected five

direct categories; OT/PT home and telephone sessions, staff training, intervention materials, therapist travel, and home modifications (ordering, installing, and quality control).

Time spent by OTs delivering the intervention was estimated to be 1.5 hours per home visit and 15 minutes per telephone call. This estimate was derived from reviewing the study design and post hoc interviews with OT study interventionists. Per-hour pay for OTs was calculated using national average rates (\$28) for OTs with one to four years experience [24], with an additional 25% added to account for fringe benefits. Also, 15 minutes were estimated to account for preparation and documentation for each session.

We estimated the time spent by the PT conducting the intervention (1.5 hr/home visit) based on a review of the study design and post hoc interviews with interventionists. Per-hour pay for the PT was calculated using the national average rate of \$31 for PTs with one to four years experience; an additional 25% was assumed for fringe benefits [24]. An additional 15 minutes were estimated to account for preparation and documentation following the session based on therapist records.

Staff training time for seven OTs and one PT was 16 hours and involved instruction in the study protocol. Similar assumptions for hourly wage rates as above were applied. Cost of training was estimated on a per-participant basis. To estimate cost on a per-participant basis we calculated the total cost of training and divided this number by the number of study participants in the intervention group.

There were two types of material costs: (1) those used by interventionists (\$5) and (2) education print materials provided to participants (\$10). Total cost of materials per participant was estimated to be \$15.

Interventionist travel expenses to and from participant homes were calculated based on an average of a 20 mile radius round trip per visit, reimbursed at the government rate of \$.51 a mile [25].

Home modification (e.g., grab bars and raised toilet seats) costs included ordering, purchasing, installing, and assuring quality.

2.5. Outcome Measure—Life Years Saved (LYS). For the cost-effectiveness analysis, we used LYS over two years as the primary outcome measure. The survival benefit of ABLE compared to control has been described elsewhere [18]. Briefly, to determine survival benefit, the number of days to death was calculated from the baseline interview until date of death or December 31, 2005 using data from the National Death Index. Kaplan-Meier method was used to analyze survival rate at two years from date of study entry [18]. Difference in area under the Kaplan-Meier curve was then used to estimate LYS.

2.6. Discounting. Because the effects of the ABLE intervention occurred over a period of two years, it is necessary to account for the time delay of the benefit as it is more advantageous to receive a benefit earlier rather than later [21, 22]. To adjust for the time delay of a benefit, we discounted our outcome measure, life years saved, by a factor of 3%.

TABLE 1: Background characteristics.

Characteristic	Control (<i>n</i> = 159)	Experimental (<i>n</i> = 160)	Total (<i>N</i> = 319)	<i>P</i>
Mean Age (SD)	78.5 (5.7)	79.5 (6.1)	79.0 (5.9)	.158
Race (%)				.387
White	52.2	53.1	52.7	
African American	45.9	45.0	45.5	
Hispanic	0.0	1.3	0.6	
Other	1.9	0.6	1.2	
Gender (%)				.751
Male	18.9	17.5	18.2	
Female	81.1	82.5	81.8	
Living arrangement (%)				.462
Alone	59.7	63.8	61.8	
With others	40.3	36.3	38.2	
Education (%)				.916
< High school	37.7	35.6	36.7	
High school	30.2	31.9	31.0	
> High school	32.1	32.5	32.3	
Mean number of health conditions (SD)	7.1 (2.8)	6.7 (2.7)	6.9 (2.7)	.295
MMSE	27.0 (1.8)	26.8 (1.8)	26.9 (1.8)	.346

MMSE: Mini-mental status examination.

Costs were not discounted because they were incurred only during the first year of the study.

2.7. Incremental Cost-Effectiveness Ratio (ICER). The ICER was calculated by taking the difference in cost between the intervention and the control group divided by the difference in survival benefit between treatment and control groups [22, 23]. The ICER therefore represents the additional costs to bring about one life year saved from the intervention compared to usual care.

2.8. Sensitivity Analyses. In order to account for uncertainties in our model, probabilistic sensitivity analyses (PSA) were performed on both Models 1 and 2. To conduct a PSA, each variable in the model is assigned a mean and distribution around its mean. TreeAge Pro 2009 was used to calculate the PSA. To derive the results of the analysis, the mean incremental cost and effect, TreeAge Pro 2009 runs 1000 microsimulations. During each simulation, the computer uses the distribution around each variable to generate average costs and effects. Based on the average costs and effects over 1000 microsimulations, the computer then estimates the mean incremental cost and effect. Results from the PSA are presented as an acceptability curve. The acceptability curve graphically illustrates the probability of the intervention being cost effective over a range of willingness-to-pay values.

To be consistent with the methodology of the PSA, each variable in Models 1 and 2 was assigned a distribution of

values based on the standard deviations calculated during the initial study. However, for some variables (e.g., occupational therapist time on phone), data was not uniformly available from the clinical trial. For these cases, we derived estimations from consulting with research staff or the literature.

3. Results

3.1. Study Participants. Characteristics of the study population have been presented elsewhere [15]. Briefly, there were no large or statistically significant differences between intervention and control group participants at baseline on demographic and health variables (Table 1).

3.2. Cost. Total cost of ABLE per participant was \$942 (Table 2). Cost for the no-treatment control group was \$0 given that no program treatment was received. In Model 2 (base case + 10%), cost of ABLE was \$1,036.

3.3. Outcome Measure—Life Years Saved. By two years, 30 study participants had died; 9 deaths in the intervention and 21 deaths in the control group. Based on previously published Kaplan-Meier survival analysis [18], the intervention group (*n* = 160) had a survival rate of 94% (*n* = 9 deaths) reflecting a mortality rate of 6%; this is in comparison to the control group (*n* = 159) which had a survival rate of 87% or a mortality rate of 13% (*n* = 21 deaths; *P* = .02). The difference between mortality rates represents the additional survival benefit of ABLE.

TABLE 2: Cost categories for ABLE program.

Cost categories	Cost (range)
(1) Time spent with ABLE participants	
OT preparation	\$57 (\$44–\$67)
OT contact	\$299 (\$239–\$359)
PT preparation	\$10 (\$8–\$12)
PT contact	\$58 (\$46–\$69)
(2) Training	
OT/PT	\$5 (\$4–\$6)
(3) Materials	
For OT/PT	\$5 (\$4–\$6)
For participants	\$10 (\$8–\$12)
(4) Travel	
Mileage	\$61 (\$49–\$73)
(5) Home modifications	
Modifications	\$439 (\$351–\$527)
Total average cost per person	\$942

3.4. *ICER and Sensitivity Analysis of ICER Estimate.* Under the assumptions of Model 1, the ICER (cost per one additional year of life) was \$13,179 and under the assumptions of Model 2, the ICER is \$14,800.

Figure 1 details the acceptability curve for Models 1 and 2. Based on the acceptability curve and under the assumptions of Model 1, ABLE is cost effective greater than 50% of the time as long as a purchaser is willing to pay more than \$13,000 for one additional year of life. Under the assumptions of Model 2, ABLE is cost effective greater than 50% of the time as long as the purchaser is willing to pay more than \$14,800 for one additional year of life.

4. Discussion

To our knowledge, this is one of the first cost-effectiveness analyses of a home-based intervention tested in the USA which reduced functional difficulties and mortality risk in vulnerable older adults. The original ABLE trial did not include cost as a study aim and thus the cost analyses presented here were post hoc and hence necessarily exploratory. Our study demonstrates, however, the value of conducting cost analyses even post hoc to derive preliminary economic conditions of effectiveness and enhance the implementation potential of existing proven programs for vulnerable older adults. There are two key findings from this study. First, ABLE's cost effectiveness is within an acceptable range of willingness to pay (WTP) values identified in previous related studies, although research is very limited in this area. Second, the cost of ABLE is reasonable and compares favorably to other nonpharmacologic, home-based interventions for older adults.

Traditionally, cost-effectiveness analyses use quality-adjusted life years (QALYs) as the primary outcome measure and apply a WTP threshold of \$50,000 per quality-adjusted life (QALY). However, in ABLE, QALYs were not captured

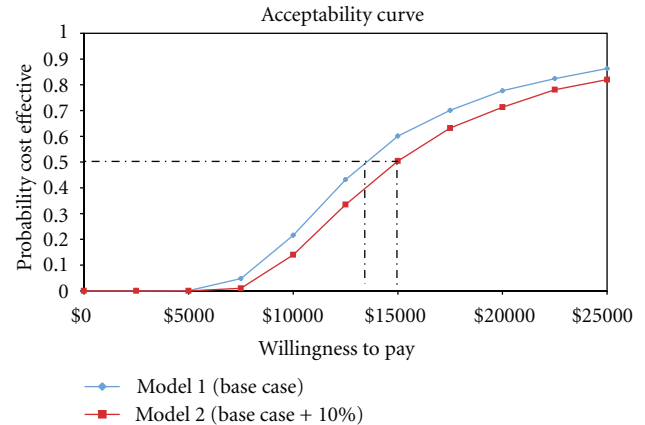


FIGURE 1

in the original trial, a potential limitation of this economic study. Thus, we were unable to use this standard metric to evaluate cost effectiveness. To aid in the interpretation of our findings and compensate for the lack of QALY outcomes, we searched the literature for studies which evaluated WTP for interventions that decrease mortality. By searching for established WTP values, we sought to determine the value of one additional year of life, as reported in the literature. Applying WTP values published previously to ABLE provides a preliminary contextual basis for understanding our derived ICER estimates.

Our search yielded only two studies that can provide some insight as to WTP for ABLE [26, 27]. Johannesson and Johannesson [26] estimated the WTP (\$400–\$1500) for a one-year increase in life expectancy of a hypothetical intervention. Taking the average of this range (\$950) and adjusting for inflation, we arrived at an estimated WTP of \$1,299/year. Applying Johannesson and Johannesson WTP estimate to the acceptability curve generated in our study, ABLE would not be cost effective under either Model 1 or Model 2 [26].

However, Johannesson and Johannesson WTP estimate was low compared to other published studies [26, 28]. One possible explanation for the low estimate is that Johannesson and Johannesson surveyed a Swedish population and, thus, their preferences may not be the same as a US population. In addition, the population surveyed was younger (<69) than the ABLE population (mean age 79).

In another study, Johnson et al. evaluated WTP by asking respondents how much they would be WTP for one additional year of life based on six quality of life scenarios (no physical limitations and no social limitations, some physical limitations and no social limitations, some physical limitations and some social limitations, home bound, need help, and in hospital) [27]. The authors found that individuals were willing to pay the most for the scenario in which they had no physical or social limitations. The ABLE population could be described as having some physical and social limitations [15, 16]. Johnson et al. found the WTP interval (after adjusting for inflation and currency exchange rates) for this subgroup to be between \$1,754 and 17,556. If

we were to apply the upper range ($> \$14,800$) of the Johnson et al. WTP estimates to our acceptability curve (Figure 1), ABLE would be considered cost effective greater than 50% of the time.

Although the WTP data that is applicable to ABLE is limited, these two studies provide some basis for contextualizing the ABLE ICER estimate. While it is difficult to make generalizations about the cost effectiveness of ABLE given limited WTP data, utilizing the acceptability curve (Figure 1), an individual decision maker can determine the probability of ABLE being cost effective given their own WTP. More importantly, the dearth of WTP data indicates the need for future studies to collect and report on such values for older adults with late-life disability.

The cost of implementing ABLE relative to similar programs is also difficult to evaluate as there are limited studies on the cost of similar novel home-based interventions. An OT program for well elderly reported average program costs of \$548 per participant with cost per QALY for the intervention estimated at \$10,666 [12]. While average costs for ABLE were \$400 higher, the difference is chiefly due to costs associated with specialized equipment (\$439) important to vulnerable elders or those aging at home with functional difficulties.

ABLE also compares favorably to an OT dementia caregiver intervention tested in The Netherlands [13]. Intervention costs per patient in The Netherlands study were \$1,738 (USD), and the intervention was found to be successful only 36% of the time.

Finally, ABLE compares favorably to The Geriatric Resources for Assessment and Care of Elders model (GRACE) [11]. GRACE is 2-year home based care management intervention designed to improve quality of care and reduce acute care. The mean cost of GRACE per patient per year was \$1,000 [29], almost identical to ABLE. However, unlike in ABLE, there was no statistical difference in mortality rate between the intervention and control arms of the GRACE study.

As this is a post hoc study, we were unable to derive real-time costs, a study limitation. Our method for estimating the cost of delivering ABLE was based on a review of the study protocol and interviews with intervention staff. Although we were thorough in our analyses, we believe that our cost estimate may in fact overestimate the cost of ABLE because it does not take into account potential cost savings. For example, those in the ABLE group benefited from a decrease in functional difficulties and mortality. Thus, there is a strong possibility that those in the ABLE group compared to the control group actually used less health care services. Unfortunately, the original data does not lend itself to an estimate of health care utilization, a significant limitation.

Several other study limitations should also be noted. First, we were unable to conduct our analyses from a societal perspective and, thus, some may view this as major study limitation. Secondly, traditional cost-effectiveness analyses use QALYs as the primary outcome measure instead of QALYs, we used life years saved. Although it would have been ideal to include QALYs in this analysis, as stated above, the original parent trial did not capture this data.

In conclusion, although there are limitations to all cost-effectiveness analyses, these studies are at the forefront of a growing trend in health economics to quantify benefits of proven programs from which to make judgments as to what should be translated into real-world services. With the aging of the population, it is increasingly important to measure cost effectiveness of programs that help older adults remain independent in their homes. To advance services and policies that support aging in place, economic analyses of promising programs are important. Few existing proven programs for functionally vulnerable older adults have included cost analyses prospectively. However, we show in this study that it is possible to evaluate the cost of a proven program post hoc, although admittedly there are limitations to a retrospective approach and it is preferable to conduct such analyses prospectively. Nevertheless, our approach offers a preliminary understanding of the costs of a highly effective program. The cost of ABLE can be considered low in view of the high cost of medical and drug therapies. Also, the results from the cost-effectiveness analyses of ABLE show that the additional cost to bring about one additional year of life to older adults living at home with functional difficulties compares somewhat favorably to the very few studies conducted in this area. Future studies of ABLE and other related programs will need to be conducted in which treatment effects are measured over a longer period of time and cost analyses are considered a priori to study implementation so as to capture cost from a societal perspective. Finally, future studies that use nontraditional outcome measures need to place ICER estimates in real world context by evaluating an individual and a society's willingness to pay for such benefits.

Conflict of Interests

The authors declare that there is no conflict of interests.

Authors' Contribution

Jutkowitz conceptualized the paper and cost analyses, conducted all cost and sensitivity analyses, and had primary responsibility for preparation of the paper. L. N. Gitlin, Ph.D., was principal investigator of the original randomized ABLE trial. She provided guidance as to the description of the intervention and associated cost categories and helped to develop and edit the introduction and discussion sections of the paper. L. T. Pizzi, Pharm. D., provided consultation on appropriate cost analyses and helped to refine the presentation of the cost data. E. Lee provided consultation on appropriate cost analyses and conducted the sensitivity analyses. M. Dennis, Ph. D., helped prepare the data set for which analyses were conducted and reviewed and edited the paper for accuracy.

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Research Article

First Steps towards Evidence-Based Preventive Home Visits: Experiences Gathered in a Swedish Municipality

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The purpose of preventive home visits is to promote overall health and wellbeing in old age. The aim of this paper was to describe the process of the development of evidence-based preventive home visits, targeting independent community-living older persons. The evidence base was generated from published studies and practical experiences. The results demonstrate that preventive home visits should be directed to persons 80 years old and older and involve various professional competences. The visits should be personalized, lead to concrete interventions, and be followed up. The health areas assessed should derive from a broad perspective and include social, psychological, and medical aspects. Core components in the protocol developed in this study captured physical, medical, psychosocial, and environmental aspects. Results of a pilot study showed that the protocol validly identified health risks among older people with different levels of ADL dependence.

1. Background

Old people's health and wellbeing are urgent questions for the society of today, and ageing in place is not only a common policy but also prioritised by the majority of older persons, in Sweden as in most European countries [1]. It is of great concern that this age group receives support during the process of ageing, and evidence-based health-related interventions are important to meet the needs of health and social care in this increasing population segment. In order to develop more efficient practices, the evidence base should be taken into account, integrating practical expertise and experience with the best available scientific evidence [2].

Preventive home visits targeting community-dwelling older persons represent one example of proactive societal action that has received growing attention. The purpose of PHV is to promote overall health and wellbeing in old age, to identify people at risk for health problems, to prevent further decline, to enhance the possibility for the individual to maintain activity and participation, to be in control of everyday life, and to experience life satisfaction [3–6]. Preventive home visits have attracted political attention, and, for example, in Denmark since 1998, such activities are

mandatory by law. In Sweden, the government has allocated economic resources to all municipalities, encouraging the provision of PHV to all citizens aged 75+. Still, even if a knowledge base on research is available, few of the local initiatives are based on science and best practice. Based on an attempt to support a Swedish municipality in developing evidence-based PHV, the overriding purpose of this paper is to describe a methodological process generating recommendations for further research and practice implementation.

In the scientific literature, PHV have been described as a dynamic process between the home visitor and the visited person, aiming to sustain and improve the older person's wellbeing and independence [7, 8]. According to Danish experiences, the older person should be seen in a social and a psychosocial context, involving family and friends. That is, the Danish approach to PHV is to give equal attention to needs for health services and social support, and to risks to loose control/independence in life [9]. However, the results and effects of PHV, analysed in several review articles, are mixed and difficult to compare [3, 8, 10, 11]. Besides the fact that older persons constitute a heterogeneous group, another reason for the divergent picture of results is that there is a lack of common definitions within the field.

Different aims, methods, outcome measures, and designs of the preventive efforts have been used and described, and different disciplines value prevention differently [12].

For example, Van Haastregt and coworkers found no clear evidence of positive effects of PHV when the visits were not tailored to the older person's needs [8]. In contrast, Byles identified improved health in their review, but argued that it is hard to identify the underlying mechanism for successful outcomes [3]. Effects found by others were reductions in mortality, functional decline, and admissions to long-term institutional care and hospitals [13–16]. Further positive tendencies of health effects seen were related to activities of daily living (ADL), physical capacity, falls, and social activities [9, 17, 18], as well as aspects of participation and life satisfaction [5, 19]. These somewhat inconclusive results still indicate that the use of a multidimensional approach including medical, psychosocial, functional, and environmental areas seem to increase the possibilities for successful preventive effects. Other aspects of a successful intervention were that several home visits with each individual are necessary [4], and that training of the professionals involved is important [20]. Still, the overall effect of PHV is uncertain and valued in divergent ways. As yet, there is limited evidence regarding the content, design, and structure of successful approaches to PHV and the literature on how to successfully operationalize the existing knowledge base is scarce. Therefore, it is crucial to develop and evaluate efficient structures for PHV, in order to ensure efficient quality development based on scientific evidence and best practices.

The aim of this study was to describe the first steps of the development of evidence-based PHV targeting independent-living community-dwelling older persons in a Swedish municipality. The specific aims were to

- (i) identify the existing best evidence base for a PHV protocol,
- (ii) develop and present the content of a protocol,
- (iii) pilot the developed protocol, that is, describe the piloting procedures and present results in terms of face and convergent validity, feasibility, and sensitivity for the detection of health problems.

2. Methods

Starting out from Sackett's definition of evidence-based practice [2]; that is, the integration of practical experiences and best available scientific evidence, this project was composed of different parts (Table 1). The development-evaluation-implementation process as outlined by Craig et al. [21] served as the methodological framework of our study. It comprises structured guidelines serving to help practitioners and researchers to systematically recognise and adopt appropriate methods when developing, evaluating, and implementing complex interventions to improve health. A key message is to give weights to the development and implementation phase of the intervention, as well as to the evaluation, not necessarily following a linear sequence. The current study was concentrated on the development of the

content and design of a PHV protocol, followed by a first pilot test. Additional and necessary steps such as evaluation and implementation are not within the scope of the present paper.

2.1. Project Context and Organisation. The study was carried out in a large municipality in southern Sweden (126,000 inhabitants; 17% aged 66+, 5% 80+). The study was initiated by the Department of Social Care of older people in the municipality, and carried out in cooperation with researchers at Lund University (authors). In the municipality, there were prior experiences within the social care sector of providing PHV through a project financed by governmental development grants. The target population for the PHV activities was community-living persons in ordinary housing, 80 years of age or older, and independent of health care or social services from the municipality for their daily activities. At the prospect of the current study, municipality administrators and politicians decided to raise their ambitions and explore the possibilities to introduce an evidence-based approach to PHV. Subsequently, a formal agreement between the university and the social services administration was made, involving an administrator at the preventive unit within social care and a senior scientist (last author) at the university as the responsible parties.

A project group was established, consisting of experienced social carers employed in the Department of Social Care of older people in the municipality and researchers representing physiotherapy, occupational therapy, and gerontology at the university. One of the researchers was appointed project leader (second author). Two advisory boards were established; one in the municipality and one in the university. An internationally acknowledged scientific expert in research on PHV served as an external consultant to the project. The intention of the PHV to be developed was that the PHV protocol should be possible to introduce in everyday work in Swedish social care municipality contexts. The preparation phase targeted financing and collaboration issues, prior to the formal agreement.

2.2. Procedure. The process described in this paper consisted of three phases: (1) synthesis of the evidence base for PHV; (2) development of a protocol for PHV; (3) piloting of the PHV protocol, followed by revisions.

2.2.1. Synthesis of the Evidence Base for PHV. Initially, a review of randomized control trials (RCT), identified by means of two recent and comprehensive systematic meta-analyses [4, 16], was performed, applying a two-step procedure. After exclusion of four articles, due to lack of required outcome measures (data on health aspects or relocation, hospitalisation, and mortality) and shortcomings in the follow-up procedure of the PHV, 21 trials remained and were analysed by means of an exploratory approach. That is, the material was reviewed in depth, to classify each original trial as either having or not having a positive effect on health, and in this way we were able to identify factors associated with general importance of successful PHV programs when

TABLE 1: Project description.

Project part	Method approach	Participants
Identifying the evidence base		
(i) Literature review	Exploratory approach	First and second author
(ii) Group discussions	With inspiration from focus group interview methodology	12 older people, first author
(iii) Previous experiences in study district	Descriptive	First and second author, municipality employees
(iv) Seminar	Discussion	External consult, research team
Construction of the PHV protocol		
(i) Group discussions on regular basis	Iterative process	Research team, municipality employees Advisory boards, external expert
(ii) Education and training		Second author, municipality employees
Pilot study	Empirical	16 older people, first and second author, municipality employees

analysing all 21 trials together. Next, additional information from a set of state-of-the-art publications, that is, two cohort studies and one meta-analysis [4, 22, 23], was extracted and integrated in the evolving synthesis.

In order to capture viewpoints from the target group for PHV, two group discussions were performed, inspired by focus group interview methodology [24]. For one of the group discussions, older persons living in ordinary housing in the municipality, and with previous experience of PHV, were recruited in the following way: every tenth person that had been visited the year before was phoned and asked to participate until five persons, interested to share their experiences in a group discussion, had agreed (mean age 85 years). Participants for the other discussion group were recruited from different local organisations of senior citizens. Seven older persons volunteered, having an interest to share their views and ideas regarding PHV; none of those had any prior personal experience of PHV. The group discussions were performed at a local meeting point for seniors and lasted about two hours each. The discussions were initiated by giving information about previous PHV activities in the municipality. The project leader led the group discussions. Questions in the group sessions concerned views on the aims of a PHV, and health areas to be included. The group members shared personal experiences; pros and cons, timing

of PHV, the preferred location for the interviews, how the home visits and interventions should be accomplished and designed, and the group to target. Notes were taken and confirmed with the participants by the group leader directly connected to each session. The participants' viewpoints were analysed by the group leader who summarised and condensed the content into areas relevant for PHV.

In addition, prior experiences of PHV within the social sector in the municipality were collated in a report, constituting descriptive data of persons receiving such visits. This description of the target group, their needs, and what information and services had been distributed in connection with the PHV served as an important input to the evidence base.

Utilising the different types of data and information thus collected in an integrated manner, the synthesised evidence base was subsequently established, involving the two projects groups in iterative discussions. In addition, the material was discussed in a seminar involving the external consultant and additional researchers at the university.

2.2.2. Development of a Protocol for PHV. In the construction phase of the protocol of PHV, the evidence base that was defined (as described above) was taken into consideration and used. Researchers and municipality employees met on a regular basis in an iterative process, involving identification of different health assessments, followed by education and training in how to administer such instruments during PHV. The content of the protocol, its design, and level of structure were intensively discussed, as were possible scales and questions to be included. Moreover, the advisory boards as well as the external expert were involved in the development process.

The final, structured PHV protocol, described in the results section, consisted of questions and assessments for different health areas. Guiding instructions to the home visitor were included in the protocol. The protocol also included suggestions for possible interventions based on the information collected, but this part was not piloted and is thus not further accounted for in the current paper.

2.2.3. Piloting of the PHV Protocol. In order to pilot the PHV protocol, a strategic sampling procedure was performed, aiming at identifying 20 persons, 80 years of age or older, representing different levels of independence/dependence in ADL. The sampling was accomplished by a comparison of the population register against the social services register, the latter showing persons in use of alarm and home services. The strategy was to involve both men and women, in different living situations and housing conditions. Most important, persons with different levels of ADL independence were to be included, assuming that person with less ADL capacity had more risk factors, that is, in order to be able to study whether the new PHV protocol was able to detect persons with decreased health and/or health risks, allowing for piloting also of the in-depth questions/assessments in the health areas included [25].

In total, 49 invitation letters were sent out to potential participants. Forty-two of them were possible to reach by

telephone and asked to participate in the pilot study. Twenty-six declined participation (17 of those were single-living women), mostly due to lack of interest, or time, or due to having health problems. Those who accepted participation and gave informed consent during the phone call were asked questions from the ADL Staircase assessment [26]. Finally, the sample consisted of 16 persons (13 men and three women, median age 83 years, range 80–92), categorised into three groups: independent in ADL, $n = 11$; dependent in I-ADL only, $n = 3$; dependent in both I-ADL and P-ADL, $n = 2$. Seven persons were married, nine were single-living (six men, three women).

Formal ethical approval was granted by the regional ethical review board (Dnr: 2009/516). Written informed consent was given by each informant in the study, after receiving information on the possibility to withdraw from the study at any time without having to state a reason.

The home visits were accomplished by four different home visitors; two experienced social carers and two researchers (occupational therapist, physiotherapist) from the university. All home visits had the same structure, following the new PHV protocol. The time used for each home visit was registered, and the visitors also recorded viewpoints of the PHV protocol, based on their experiences of each home visit, including comments from the older persons themselves.

For the data analysis, two of the ADL groups were merged combining those being independent with those dependent in I-ADL, that is, all those persons that were independent in P-ADL and thereby represented the target group for PHV. The results of the assessments included in the PHV protocol were analysed by means of descriptive statistics. In order to assess convergent validity, the median number of identified health risks was calculated for each ADL level group and the relationship between ADL level and number of identified health risks was analyzed. Moreover, to assess the sensitivity of detecting health problems for each health area included in the protocol, the total number of risks within each health area was identified. Time use was accounted for in minutes. The qualitative data (visitor experiences) was organised in a scheme, categorising the viewpoints recorded in technical, practical effectiveness, and more comprehensive aspects. Likewise, viewpoints from the visited persons were analysed. The analyses of quantitative and qualitative data [27] formed the basis for a revised version of the PHV protocol, constituting the end product of the part of the project presented in the current paper.

3. Results

3.1. Synthesis of the Evidence Base for PHV. The review of RCT studies ($N = 21$) showed that there was a tendency favouring interventions targeting higher age groups. That is, in the seven trials targeting a population with a mean or median age of 80 years of age or older, four demonstrated positive effects on health, compared to four out of 14 of the trials targeting a younger population. In the eight trials where they reported making home visits according to need, five had a positive effect on health versus three out of

thirteen in those who did not. It might be important to have two or more professions represented in the team of home visitors. Out of eight trials reporting two professions or more making home visits, half of them had positive effects versus one-third of those trials where only one profession was represented. Our analysis of the health areas related to health effects included in the screening (from a set of state-of-the-art publications), concluded that information on medical, social, psychological, functional capacity, and environmental aspects were areas vital to screen.

The results of the group discussions implied that PHV should be performed in the person's home, be open in nature, and the staff should have enough time in order to detect needs in terms of health risks. Those who had prior personal experience of PHV expressed the importance of continuity, that is, that the same person was making repeated visits in order to attain confidence. The visit should contain both information and guidance since the health care and social services organisations are hard to understand, and knowing where and whom to turn to was perceived as hard to grasp. Overall according to both groups of older persons participating in the discussions, knowledge is lacking about what help and assistance is possible to receive, and what possibilities for meetings and activities for older persons are available. Stigmatizing aspects in contacts with the municipality, in particular with the social sector, were pronounced as an interfering factor for accepting PHV. The participants also stated that attitudes among older people themselves have to be changed in order to succeed in having more people being prepared to accept PHV.

3.2. The Protocol for PHV. Based on the synthesised evidence base, core components in the protocol consisted of health areas capturing physical, medical, psychosocial, and environmental aspects, described in detail in Table 2. The health areas chosen had similarities with those previously used for PHV in the municipality, but were extended, made more structured, and were based on established assessment instruments, and did also include new areas such as cognition, depression, and physical capacity.

Each health area of the PHV protocol was introduced with an open question in order to start the discussion, followed by structured questions or assessments. That is, when a person at risk was identified by means of predefined cutoff levels, in-depth follow-up questions or assessments were administered. The aim of the in-depth questions/assessments was two-fold: to secure that the assessment had captured a problematic health area, and to guide forthcoming interventions (while as such not included in the current study). For each health area the PHV protocol comprised a manual to serve as guidance for the home visitor and to provide in-depth information, followed by a suggestion on how to interpret the assessment results. Since staff with different professional training could be involved in PHV in the practice context, the degree of structure of the protocol ended up higher than initially intended. As far as possible, well-established and valid assessments and questions were chosen for the protocol. These decisions were taken in order to strengthen validity and reliability aspects.

TABLE 2: Contents in PHV protocol administrated in the pilot study.

Health area	Assessment	Rationale/source	Structured questions ^a (q), n		Criterion for using in-depth questionnaire
			Basic q	In-depth q	
Descriptive questions			5		
ADL	ADL Staircase	Items selected from the ADL-staircase [26]. Questions on difficulty were added [28].	5	1	Having difficulties in one or more I-ADL.
Comfort in home	Usability in My Home (UIMH)	[29, 30].	10	0	
Activities/interests	Study specific	The relation between meaningful activities and wellbeing is well established [31]. Open ended q on possible changes in pattern of activities and interest were used.	3	0	
Exercise	Study specific	Absence of physical exercise has showed to increase the risk for functional decline. Structured q on level of physical activity [32–36].	4	0	
Social contacts	Study specific	Used as a predictor of functional decline [22].	4	5	Not having anyone to contact if necessary or expressing feelings of loneliness.
Pain	SF-36	Based on clinical experiences [22], SF-36 were used [37], in combination with one q on pain in the feet.	2	4	Expressing moderate or worse pain.
Depression	GDS4, GDS20	Used as a predictor of functional decline [22].	4	16	Suspected depression (short version; GDS4).
Falls	Study specific	Q for screening of increased fall-risk and in depth assessment of potential causes of falls were based on risk-factors for falls identified by Ganz et al. [38]. *Part of SPPB-S, used as a predictor of functional decline and relocation to nursing home [22, 23]. SPPB-S [39] was used as part of the in-depth assessment of potential causes of falls.	4	13	Having had a fall during last year in an everyday situation or having trouble with walking, balance, or moving.
Pain/physical tests	SPPB-S	Used as part of the potential causes of falls [38]. Housing Enabler, entrance, and indoors sections [40].	*Practical test	Practical test	
Environmental barriers	Housing Enabler Screening tool	The connection between cognitive and functional decline is strong [22]. Short and long version of MMT (Minimental test) were used [41].	36	0	
Cognition	MMT		9	11	Suspected dementia (short version of MMT).
Medication	75+ health assessments	Selected from an Australian guide for health assessments [42].	5	Open-ended questions	Use of >3 medications in combination with difficulties remembering, lack of a physician contact, or using medication for anxiety, distress, or sleeping disturbance.
Food, diet	MNA	Mininutritional assessment (MNA).	6	9	Risk for malnutrition (MNA).

TABLE 2: Continued.

Health area	Assessment	Rationale/source	Structured questions ^a (q), n		Criterion for using in-depth questionnaire
			Basic q	In-depth q	
Health (perceived)	SF-36	Perceived health is a well-established predictor for mortality [22, 43]. One item from the SF-36 was used [37].	2	0	
Vision and hearing	Study specific	Used as a predictor of functional decline [22]. Identified as an important health factor in group discussions	2	0	
Evaluation q to the informant	Study specific		5	na	
Evaluation q to the interviewer	Study specific		10	na	

^aEach section starts with an open question introducing the topic, that is, *How do you manage everyday activities in your home?* or *Do you feel comfortable in your home?*

na = not applicable.

3.3. Piloting of the PHV Protocol. The time use for administering the new PHV protocol varied between 45–130 minutes (median 90 minutes), with no differences between the three ADL level groups. For those PHVs where the visited person qualified for and responded to in-depth questions/assessments (one or more), the median time use was 120 min (range 90–130). The visited persons regarded the time use as reasonable, as did the home visitors.

In total, 48 health risks, within all health areas, were detected by the protocol ($M = 3$, $SD \pm 2,3$), distributed on ADL, other activities, social contacts, pain, depression, falls, impaired cognition, physical capacity, sight, or hearing (Table 3). The number of identified risks within each health area in the total sample varied from 1 to 10. Those participants' independent in P-ADL had the highest proportion of their identified health risks referring to pain, fall, hearing, and physical capacity. The lowest proportion referred to, in all ADL-level groups, was social contacts, nutrition, depression, and cognition.

In the total sample, the number of health risks per person, according to ADL level group, varied between 0 and 8, indicating that the protocol had sensitivity for detecting health problems. The median number of health risks identified per person was twice as high in the dependent I-ADL group compared to the independent, indicating the convergent validity of the protocol. The median numbers of identified risks in the four ADL level groups are presented in Table 4.

3.3.1. Revision of the PHV Protocol. The overall point of view from the visited persons was that the questions were good and easy to understand and answer, even though three persons stated that the questions had several limitations. For example, some of the questions were experienced as hard to answer, they lacked information concerning health services and leisure possibilities for older people, and they thought that discussions regarding married life or more extended questions on memory issues were missing. These viewpoints

were strengthened by the fact that examples of areas not included in the PHV protocol (health services, supports to relatives providing care, and meeting places for older people) spontaneously surfaced and were discussed during the home visits.

After the piloting the home visitors made a concluding evaluation of the protocol. A number of additional issues, mostly related to the structure of the protocol, were discussed by the home visitors and suggested for revision. Their points of view revealed that in most part the protocol was feasible to handle. However, aspects such as the protocol being too comprehensive and hard to navigate were also expressed. Concerns were raised regarding loneliness, weight, and medication as such questions had been felt too direct to ask, and the assessment of parts of the private home environment for barriers had resulted in similar reactions. On the other hand, questions on drinking habits and medication were suggested to be asked to all participants, instead of just being part of in-depth sections. Questions on P-ADL were not considered optimal; it did not seem adequate to ask independent persons about their need of help.

In accordance with the specific study aim to present the content of a protocol for PHV, the protocol was revised based on the piloting. Most adjustments and changes were made in the areas of ADL and falls. The revised version contained the same health areas as the version piloted (Table 2), however optimized. Moreover, a suggestion for the future was to place the visitor instructions and in-depth questions/assessments in a separate manual, in order to facilitate navigation in the PHV protocol.

4. Discussion

The process described in this paper was accomplished in close collaboration between Swedish municipality practice and researchers, producing results with the potential to foster the development of evidence-based PHV in similar settings [2]. Even if the current study was delimited and represents

TABLE 3: Number of identified health risks within each health area in the PHV protocol in the pilot study, in total and according to ADL-level group, $N = 16$.

Health area	Independent in ADL, $n = 11$	Dependent in I-ADL, $n = 3$	Independent in P-ADL, $n = 14^a$	Dependent in P-and I-ADL, $n = 2$	Total sample, $N = 16$
ADL	1	1	2	2	4
Activities/interests	1	1	2	2	4
Social contacts	1	0	1	0	1
Pain	3	3	6	2	8
Depression	0	0	0	1	1
Falls	3	3	6	2	8
Cognition	0	0	0	1	1
Medication	1	2	3	1	4
Food/diet	0	1	1	0	1
Physical capacity*	4/9	0	4	0/1	4/13
Vision	1	1	2	0	2
Hearing	6	2	8	2	10
Summa	21	14	35	13	48

P-ADL = personal activities of daily living.

I-ADL = instrumental activities of daily living.

*The last figure states the total number of persons within the ADL-level group that performed physical tests, since not all persons did.

^aThe groups independent in ADL and dependent in I-ADL merged comprising all persons independent in P-ADL.

TABLE 4: Median number of health risks identified in the pilot study, according to ADL level group, $N = 16$.

ADL level group	Median	Min–max
Independent in P-ADL, $n = 14$	2.5	0–7
(i) Independent in ADL, $n = 11$	2.0	0–4
(ii) Dependent in I-ADL, $n = 3$	4.0	3–7
Dependent in P- and I-ADL, $n = 2$	6.5	5–8

P-ADL = personal activities of daily living; feeding, transferring, toileting, dressing, and bathing.

I-ADL = instrumental activities of daily living; cooking, transporting, shopping, and cleaning.

only the very first steps of a long-term comprehensive project, it constitutes a first step towards an RCT. Currently, even if there is a sound base of scientific literature on PHVs available, PHV projects are being carried out in Sweden and in other Western countries mostly based on experience-based knowledge and practice. Since the uptake of research results in practice contexts in health care and social services is known to be insufficient, even if the current study is minor in scope it is an example of interaction between practitioners and researchers that might prove efficient in the forthcoming development of PHV.

Pilot testing of the PHV protocol indicated that the convergent validity is acceptable. That is, since the number of identified health risks increased with poorer health, indicated by the ADL Staircase, health risks can be identified with the PHV protocol, which is in accordance with the intention of PHV to older people living in the community [8]. The

median number of health risks identified among participants independent in P-ADL is in line with previous studies [42, 44, 45]. Since the health condition and functioning of older people are not static conditions [46], preventing ill-health is an ongoing process. In this kind of long-term work, it is important to identify health areas that may be added over time [47]. The results from a previous study of PHV show that for each year, new major health problems were identified in approximately one-third of the older persons visited [48].

It is widely accepted that ADL is an important health aspect and has strong support as a valid indicator of health among older people, even though it does not cover all aspects of health [49, 50]. Some disadvantages in the ADL-Staircase instrument [26] can, however, be discussed, even if the results indicate that the instrument can be used to identify health risks and differentiate health status among groups of older people. One disadvantage is that the scale is not very sensitive, since it is based on a crude assessment of dependence and independence. Previous research has shown that the discrimination between different levels of ADL ability can be improved by adding a self-rated assessment of the difficulty associated with the performance [28]. Since the target group of PHV is persons independent of municipality services, with a specific focus to prevent health problems, there is reason to consider revision of the applications of the ADL-Staircase in the PHV protocol to increase the sensitivity for detecting changes over time. While not yet tested, it is reasonable to assume that such an improved PHV protocol can be used to also identify additional health problems in individuals over time. Longitudinal studies are, however,

required to determine this type of sensitivity. In a study such as this where the participants only were studied at one occasion, the fact that more risk factors were identified in a group of older people with worse health (dependent in I-ADL) than in a group with better health (independent in ADL) is, however, an indication that the protocol is sensitive to also identify changes over time, and even better after further optimization.

The diversity of methods used in the current study, as implied by the guidelines of developing and evaluating complex interventions [21], was valuable for strengthening the content of the PHV protocol. The synthesis of the evidence base so far accomplished has implications for how to design and structure forthcoming PHV studies. Our suggestion is that an intervention group should receive PHV, alongside a control group receiving “usual treatment” involving general written community information but no followups or tailored interventions. The PHV practice should involve a multiprofessional team of visitors and contain at least two home visits per person and year on a regular basis, screening each individual for health risks. It is important to be aware of the complexity of the health and social services and diversity of the population segment for which PHVs are targeted. The preventive work in the intervention group should focus on individually tailored interventions with close followups targeting the oldest population, that is, 80 years of age and above. Outcome variables for PHV recommended in recent literature are self-perceived health, difficulty and dependence in ADL, participation, hospitalization, empowerment, falls, and control beliefs [4, 16, 22, 23]. Presumably, there are gains to be made from also including nonmedical aspects to a greater extent in PHV interventions while in the search accomplished prior to our project, no such literature was identified.

Despite considerable efforts, we did not succeed in recruiting a larger sample with sufficient diversity, validly reflecting the target population. The low number of participants in the pilot study is a serious limitation, especially since those being partly dependent in ADL were very few ($n = 3$). In addition, only three of the 16 participants were women, even though there are far more women than men in the population aged 80 or older. Consequently, the results from the pilot study should be interpreted with caution; they mainly serve to test the protocol. The protocol may serve as an inspiration for further work, however, additional development and testing are needed to achieve sufficient validity, taking into account the heterogeneity of the target population as well as the need for focusing on effects and outcomes of PHV.

As to the feasibility of the protocol, it should be noted that none of the participants felt that the home visits took too long. In a previous Swedish study, demonstrating positive results of PHV, the duration of the home visits reported was 60–180 minutes [13], compared to 45–130 minutes in the present study, implying that our method is time efficient. Furthermore, none of the participants felt that the home visits were too intrusive even though they contained potentially sensitive issues. For example, it is worth noting that participants asked for more questions related to memory and

married life in old age. A few of them hesitated to perform physical testing and to allow screening of accessibility in their home. It is, however, reasonable to expect some internal drop-out when using such a comprehensive protocol. Such drop-out does not necessarily imply that the area in question should be removed from the protocol, since there will always be questions or areas not suitable to certain individuals or occasions. Participants that sought information about health care, municipal services and voluntary work were high. This kind of information was also given in prior PHV activities in the municipality and should therefore be included.

In this paper, the home visits were performed by different health care and social services professionals, all accustomed to visit and talk to old persons and to identify problems in a nonstructured way. This might have influenced the results of the pilot study in the sense that the shortcomings in the structured protocol to some extent were compensated for, that is, by the interviewers' communications skills and sensitivity to old people's health and social needs. In the discussions that took place after the data collection, the diversity in professional background was regarded as an advantage. This is in accordance with the multidimensional approach for preventive home visits suggested by others [4, 8, 16]. It should be noted, however, that for a long time in Sweden, medical competence (physicians) is not part of the municipality organization and responsibility, but rests within the county council. Consequently, involvement of general practitioners or geriatrics would imply even greater complexity and challenges beyond what was possible in this small project.

Among those participants independent in P-ADL, a large proportion with health risks in the areas of physical capacity, falls, hearing, and pain were identified. Despite the caution needed in the interpretation due to the small sample size, we note that that the proportion identified is reasonable in comparison to previous studies [44, 51]. There is evidence that reduced physical capacity increases the risk of ill-health, but just asking older people themselves to estimate their physical capacity is not reliable [22]. Therefore, reduced exercise capacity was assessed by the SPPB [52] in this study.

Barely half of the participants experienced an increased risk of falling. The link between falls, and in particular fall injuries, and functional decline is well established [22]. The four main risk factors for fall involved in the in-depth fall assessment of the PHV protocol seem relevant since we also identified one or more of these risk factors among those assessed as having a risk of falling. Also, decreased ability to perform meaningful activities in life is known to negatively influence health [53]. Questions assessing considerable changes in the patterns of activities were therefore considered important to involve in the protocol.

It is a challenging but very important task to bring research results into practical applications/activities [54]. Studies of this nature are both challenging and informative, not only for researchers but also for the staff whose daily routines are challenged when scientific results become known. Public administrations, such as municipalities, consist of several different organizational levels with different perspectives

(political, administrative, professional, and client centered) [55], and it is obviously important to a study such as this that its goals are anchored at all levels, in order to make the intervention work in everyday practice. It also puts great demands on the researchers' ability to flexibly adjust the study to the prevailing conditions and at the same time managing the study efficiently. Even if the government has given municipalities in Sweden financial support to start PHV to older people, there are no requirements to base the activity on the best available evidence. This study demonstrates a way to initiate such work, where scientists and employers in a municipality context work together to prepare evidence base, and then develop methods to test research-based methodology in practice. It is a long and complex process to develop scientifically based instruments and procedures, test and evaluate complex interventions and then introduce them as part of everyday work [21] in a municipality. The study presented in this report represents one example of the very first phase in such a process.

5. Conclusions

Based on the results and experiences from the study and the evidence base identified, we suggest that PHV, a protocol for older people, should include health areas derived from a broad perspective and include social, psychological, and medical aspects. The PHV should be based on an interview format with open as well as structured questions that make it possible to conduct the visit and interview in a personalized way. We suggest that the protocol have one part with questions and assessments that are performed with all informants, while there are specific follow-up questions, assessments, and scales integrated into the protocol that are applied for every case where a health risk is identified. It is important to also convey information about community services, especially health care and social sciences. With the reservation that we tested the PHV protocol in a pilot study with only few participants in a nonrepresentative sample, our conclusion is that the PHV protocol developed and piloted can be used for identification of health risks among older people with different levels of ADL dependence. Most important, the PHV protocol seems to be sensitive enough to identify health risks also among older people in good health, that is, those who represent the target group of PHV in Swedish municipalities. In order to establish the validity of the protocol, further studies are needed.

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