Title

A qualitative study of the experiences of people who are homebound in the Bay Area: “It’s all limited, everything is limited.”

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Rosenwohl-Mack, A., Schumacher, K., Fang, M. L., & Fukuoka, Y. (2020). A new conceptual model of experiences of aging in place in the United States: Results of a systematic review and meta-ethnography of qualitative studies. *International Journal of Nursing Studies*, 103, 103496.

AR-M was responsible for conceiving the review, designing and refining the search strategies, and writing the initial draft of the manuscript, and she is the guarantor of the review. KS provided expert guidance on qualitative research methods and evaluation. AR-M and KS worked together on the qualitative synthesis. MF provided expert guidance on information sources and search strategies. YF provided expert guidance on systematic review methodology. All authors provided significant editorial comments on the drafts and read and approved the final manuscripts.

This paper, reproduced in Chapter 2, is comparable to the review paper or chapter typically found in a standard doctoral dissertation.

A qualitative study of the experiences of people who are homebound in the Bay Area: "It's all limited, everything is limited."

Amy Rosenwohl-Mack

Abstract

An estimated 1.6 million older adults in the United States are homebound, higher than the number living in nursing homes. Older people, people of color, and women are more likely to be homebound, as well as those on low incomes and with lower education levels. Being homebound is associated with higher rates of depression, cognitive impairment, and mortality. Despite the many challenges faced by homebound people, few qualitative studies exploring their experiences have been published. There is also a lack of conceptual clarity around the meaning of being homebound; multiple definitions have been used in previous research, making it difficult to compare and synthesize findings across studies.

The purpose of this dissertation was to explore what it is like to be homebound, and to contribute to the conceptual literature on both aging in place and homeboundness. The aims of this dissertation were:

1) to synthesize and evaluate the existing qualitative evidence on experiences of aging in place in the United States;

2) to explore experiences of homebound adults living in the San Francisco Bay Area, and to build a conceptual understanding of what it means to be homebound; and

3) to explore experiences of homebound older adults during the COVID-19 pandemic.

The primary finding of my systematic review and meta-ethnography was that aging in place is a dynamic process driven by tension between threats and agency across three core experiences – identity, connectedness, and place. In my qualitative analysis, I found that being *stuck* was at the core of the experience of being homebound. Participants felt stuck in place, stuck with inadequate help, and stuck with little control over their daily lives. Nonetheless, they also emphasized the ways in which they retained their independence, distancing themselves from negative images of aging and being homebound while demonstrating their autonomy and resilience. While most people around the world felt restricted by being stuck at home during COVID-19 shelter-in-place orders, homebound people were struggling most with decisions about who to allow into their homes. They weighed risk of infection against their abilities to cope alone or with reduced levels of help at home. Most were offered virtual services; experiences of these were mixed.

The findings of this dissertation research provide new insights into the lives of homebound people and those aging in place. They also indicate important directions for future research, clinical practice, and policy, such as improvements to home care workforce policy, support related to aging in place and maintaining social connectedness, and access to healthcare for homebound people. Improving the supports and services available to homebound people, with a particular focus on safeguarding autonomy, could help enhance quality of life and alleviate the frustration and pain associated with feeling stuck at home.

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Chapter 1 : Introduction

Organization of the Dissertation

The dissertation consists of five chapters. This introductory chapter provides an overview of existing research on the epidemiology, demographics, and outcomes associated with being homebound in the United States (US). It also outlines the rationale and methodology for the two studies reported in this dissertation. Chapter 2 is a previously published systematic review and meta-ethnography of qualitative research on experiences of aging in place in the US. In Chapter 3, I present the design and findings of a qualitative analysis investigating the experiences of people who are homebound in the Bay Area. Chapter 4 is a qualitative research manuscript based on a subset of the overall study sample from Chapter 3; I evaluate the impact of the COVID-19 pandemic on experiences of people who are homebound. In Chapter 5, I summarize the findings reported in each chapter of the dissertation and present implications for future research, policy, and practice.

Background and Significance

Around 5-7% of people aged 65 years and older in the United States are homebound, higher than the proportion of this age group living in a nursing home (Ankuda et al., 2021; Ornstein et al., 2015; Soones et al., 2017). Globally, the prevalence of being homebound among older people appears to range from 5 to 40% (De-Rosende Celeiro et al., 2017; Herr et al., 2013; Lee et al., 2022). Epidemiological studies indicate that older people, people of color, and women are more likely to be homebound, as well as those on low incomes and with lower education levels (Ornstein et al., 2015), and being homebound is associated with higher rates of depression, cognitive impairment, and mortality (Soones et al., 2017; Xiang & Brooks, 2017). Environmental factors such as entry/exit stairs, lack of elevator access, and heavy doors also contribute to homebound status (Ko & Noh, 2021; Lee et al., 2022).

However, the research evidence relating to people who are homebound is complicated by issues of measurement and definition. In the absence of a standard measure, studies have used a wide range of markers for homebound status, including criteria such as eligibility for or receipt of Medicare home health, Veterans Affairs (VA) home-based care, or local services such as Meals on Wheels. This limits study samples to the minority of homebound people who are able to access these services. Other studies ask people about their behaviors and functional status. In a systematic review on multidimensional factors affecting homebound older adults, Ko and colleagues (2021) identified two types of definitions of homebound used in the literature – “confined to home or remain inside the home” and “infrequently going outside the house” – and an overall conceptualization: “the boundaries of daily life are limited to the home” (p. 1). They note the at times subtle difference between feeling confined to the home and going out infrequently. Once a week or less is the most commonly used frequency-based threshold for homebound status, but some researchers continue to assess daily or monthly outings. This variability makes it challenging to compare estimates of prevalence and risk factors across studies.

At the root of inconsistencies relating to measurement is a lack of conceptual clarity about what it means to be homebound. A series of four German studies aimed to address this, interrogating the concept of homeboundness as part of the wider category of boundedness (Schirghuber et al., 2022; Schirghuber & Schrems, 2018, 2021a, 2021b). After completing a scoping review, integrative review, concept analysis, and Delphi validation study, they concluded that the conceptual definition of homebound includes: need for assistance exiting home and with ADLs/IADLs; feeling powerless; permanence of homeboundness; weakness; and impaired mobility. They also identified endogenous factors that reinforced homeboundness, including anxiety, depression, acceptance of one's fate, fear of falling, visual impairment, and incontinence, as well as exogenous reinforcers such as overburdened caregivers, inaccessible environment, and few social contacts. Unfortunately, given the lack of published qualitative research with homebound people, it is difficult to make further conceptual advances in this area. Nonetheless, it is clear that the meaning of homeboundness extends beyond a simple measure of frequency of leaving the home.

Clinical Definitions of Homebound

Most people who are homebound rely on home-based support, including unpaid caregiving and/or paid personal care services, home health, and home-based primary care. However, access to and coverage of these services is limited by complex and at times inconsistent eligibility requirements. Medicare regulations specify that in order to qualify as homebound and therefore eligible for home health benefits, an individual must meet two criteria: (a) they must need assistance to leave their home and/or going out must constitute a significant risk to their health; and (b) it must be difficult and usually not possible for an individual to leave their home (*Medicare Benefit Policy Manual:*

Chapter 7 Home Health Services, 2022). Patients may go out regularly and maintain this status, but only if they are attending a medical appointment, day center, religious service, or other approved activity. The guidance notes that this status is not put “at risk” by attending a day center, religious services, or medical appointments, suggesting that homebound status may be precarious and conditional, not defined purely by frequency of leaving the house but also by the qualitative nature of such excursions. For many years, homebound status had to be certified in person by a physician, creating additional barriers to access. After years of unsuccessful advocacy, this was finally expanded during the COVID-19 pandemic to include “allowed practitioners” such as nurse practitioners, clinical nurse specialists, and physician assistants, and an in-person visit was no longer required for initial assessments (CARES Act, 2020; *Medicare Benefit Policy Manual: Chapter 7 Home Health Services*, 2022). Medicare covers custodial (i.e., non-medical) care only for short periods during which home health services such as skilled nursing care and physical therapy, occupational therapy, or speech therapy are also required.

The VA uses different criteria: to receive a housebound pension and home health care services, the veteran must have a permanent service-related disability that is rated at 100% (the most severe level of the scale used; examples include service-induced cancer or amputation or paralysis of two or more limbs) and either be “permanently confined to [their] immediate location” or have a second disability rated at least 60% (U.S. Department of Veterans Affairs: Veterans Benefits Administration, 2022). Home-based primary care (HBPC) is also provided to eligible Veterans, whereas this service is still in the demonstration project phase for Medicare recipients and is therefore not universally available.

Most state Medicaid programs provide home- and community-based services (HCBS) through Section 1915(c) waivers, but HBPC is not included. Although states differ in terms of program structure and benefits offered, Medicaid prohibits the use of homebound status as a criterion for access to home- and community-based services (Medicaid Program; Face-to-Face Requirements for Home Health Services; Policy Changes and Clarifications Related to Home Health, 2016). Interestingly, there was previously a homebound requirement for Medicaid home health and personal care services, but this was judged to be in violation of the Americans with Disabilities Act (ADA). Efforts in Congress to institute a similar relaxation of the homebound requirement for Medicare home health services – for example, the Home Health Payment Innovation Act (S.3545 - Home Health Payment Innovation Act of 2018, 2018) – have not yet been successful.

Eligibility restrictions as well as limited service capacity mean that many people who are homebound are unable to access care at home. A national study found that only 12% of "completely homebound" people received primary care services at home (Ornstein et al., 2015), and 63% of home-based primary care providers report that eligibility requirements are a barrier to organizing HCBS for homebound patients who need them (Norman et al., 2018). Anecdotal evidence from advocates suggests that people are denied home health for reasons such as: they have advanced dementia and roam outdoors; they are judged to have little potential for improvement; or their function has not yet declined sufficiently to qualify. These issues are particularly concerning in light of the very high costs of care for homebound individuals (Leff et al., 2015), driven by high use of emergency healthcare and hospitalization as well as daily care needs. Those who are denied access to home-based services are unlikely to be able to use alternative sources of preventive care and may rely instead on crisis-driven urgent care. Although evidence is mixed on the effects of HCBS on hospital utilization, perhaps due to fragmentation and poor coordination, benefits of in-home primary care include lower hospitalization rates and emergency department use (Schamess et al., 2017). As well as affecting healthcare utilization, systemic barriers to in-home care are likely to negatively impact the health, wellbeing, and daily experiences of people who are homebound. Research on experiences of homebound people may be valuable in advocacy efforts to expand coverage of and access to services within the home.

Previous Literature

When I embarked on my dissertation research, there were very few published studies on experiences of being homebound. Since 2020, three papers have been published addressing the daily experiences of homebound older adults (Cheng et al., 2020, 2022; Mickler et al., 2021). Two report on the same study sample, which included 18 people aged 50 or older living in a small town and its surrounding rural communities in Virginia (Cheng et al., 2020, 2022). The results sections of these papers are predominantly descriptive, listing health conditions and mobility limitations experienced by participants and documenting their functional abilities and social circumstances. The publication of these papers represents progress in terms of increasing research interest in this area but does not provide a great deal of conceptual insight or analysis of the emotional experience of being homebound. The third paper, published in 2021, explored experiences of recipients of home-based medical care (HBMC, which includes HBPC as well as other longitudinal medical services such as palliative care) and their caregivers (Mickler et al., 2021). The sample included 13 homebound participants and 17 caregivers. The researchers recruited through a HBMC practice, and the sample was diverse in race and ethnicity. Study findings emphasized the challenges of caregiving and difficulties with accessing healthcare and home care services. Compared to previous studies with HBMC/HBPC populations that focused narrowly on healthcare experiences, this research provided a more nuanced picture of the lives of homebound people. However, since only 12% of homebound people receive HBPC (Ornstein et al., 2015), the sample represented a subset of the population that has particularly good access to healthcare. Similarly, a 2019 pilot study of just eight homebound participants receiving HBPC in the Midwest described their experiences of social isolation and barriers to social engagement (Bedard-Thomas et al., 2019).

Several older studies recruited from homebound populations, but their sampling appeared to be driven by convenience or comorbidities rather than a specific focus on homebound people's experiences. These studies address topics such as use of walking devices and advance care planning (Carrese et al., 2002; Porter et al., 2011).

In 2016, Huang and colleagues published a study of homebound patients' perspectives on technology and telemedicine. Notably, the researchers were able to recruit a sample diverse in age, gender, and race and ethnicity; this is the only study I have been able to locate including younger homebound people. The authors reported mixed feelings about telemedicine among study participants, who appreciated the convenience of remote care but feared losing the therapeutic benefits of in-person visits.

Finally, two qualitative studies published in 2021 explored experiences of homebound older people during the COVID-19 pandemic. Liu et al. (2021) interviewed five clients of a community service program in New York City and found that they experienced challenges in accessing many services, including grocery shopping, healthcare, and home care. Findings from service providers emphasized the difficulty of providing remote services to a client population of whom only 5% had internet access. A mixed-methods study by Kotwal et al. (2021) focused on social isolation and loneliness, reporting that access to technology and help with functional needs were essential for maintaining social connections. Although the increase in publications about being homebound over recent years is a positive sign, there is still very little research in this area and samples tend to be small, even by qualitative research standards.

When I began my dissertation study in 2018, the only relevant reviews published were about home-based primary care and did not shed light on other aspects of the lives of homebound people (Kim & Jang, 2018; Stall et al., 2014). Since then, two systematic reviews of prevalence, definitions, and determinants of homebound status have been published (Ko & Noh, 2021; Lee et al., 2022), as well as an integrative review on loneliness among homebound older adults (Ezeokonkwo et al., 2021). Most of the included studies in these reviews are quantitative, and the findings accordingly focus on epidemiology and statistical associations. I designed the qualitative study reported in this dissertation to explore experiences of being homebound, addressing the gap I had identified in the literature.

Study Design and Methods

The aims of this dissertation research were:

- Aim 1: to synthesize and evaluate the existing qualitative evidence on experiences of aging in place in the US and to identify knowledge gaps and directions for future studies.
- Aim 2: to explore the experiences of homebound adults living in the San Francisco Bay Area and to build a conceptual understanding of what it means to be homebound.
- Aim 3: to explore the experiences of homebound older adults living in the San Francisco Bay Area during the COVID-19 pandemic.

For my first paper (Chapter 2), I chose to undertake a systematic review with meta-ethnography, because I intended to develop a theoretical model of the experience of aging in place. Meta-ethnography is a structured methodology allowing synthesis of a large volume of qualitative data and development of new conceptual insights. I found there were very few existing qualitative studies addressing the experiences of homebound people in the US. I was only able to locate three qualitative studies published prior to 2019, all of which addressed very specific experiences: use of a cane or walker (Porter et al., 2011), advanced care planning (Carrese et al., 2002), and technology and telemedicine (Huang et al., 2016). The findings of these studies did not provide insights into the daily lives and experiences of homebound people. Conducting a systematic review of these studies would have been minimally beneficial and unlikely to generate meaningful insights. Instead, I chose to take a broader perspective. I had long been interested in the cultural narratives promoting aging in place, and I wanted to understand the experiences of homebound people not as an isolated phenomenon but as a possible outcome of the strong focus on aging in place as a near-universal ideal in the US. Since there were no existing systematic reviews of qualitative studies on aging in place, I hoped both to offer a unique and important contribution to the literature and to develop a conceptual model for comparison with my primary qualitative study findings.

For my primary qualitative study (chapter 3), I aimed to address the lack of existing qualitative literature on experiences of being homebound. Again, I was interested in producing new theoretical understandings to inform future research and practice, and I found the grounded theory approach to be best aligned with this intention. The philosophical basis of grounded theory is symbolic interactionism; the two constitute a theory-methods package (Blumer, 1969; Charmaz, 2014). At the heart of symbolic interactionism is the idea that meanings are revealed, generated, and altered through interaction with other people. Denzin defines symbolic interactionism as “a theory of experience and a theory of social structure” (Denzin, 2008). In practice, symbolic interactionism directs grounded theorists to focus on identity, agency, and social action, as well as closely examining use of language (Charmaz, 2014). Symbolic interactionism is aligned with my interest in the ways in which subjective meanings related to homeboundness emerge through interactions with others and in how naming informs knowledge and action, specifically in relation to eligibility criteria and diagnostic labelling. Morse (2016) notes that grounded theory is well suited to exploring transitions and processes in health and illness. Indeed, Charmaz’s early work on experiences of chronic illness employed grounded theory to explore suffering in the form of loss, limitations, and disrupted social relationships, particularly in relation to self-concept, and her sample included homebound adults (Charmaz, 1983). I also hoped to compare my findings to existing regulations or definitions related to being homebound, adding nuance to current conceptualizations of what is meant by this status.

Based on my evaluation of the gaps in the existing research literature, I planned to expand my study sample beyond older adults, so my eligibility criteria included anyone aged 18 or older. Similarly, I wanted to interview a wider selection of homebound people than those who already receive HBPC. I planned to recruit as widely as possible, and I chose to include participants who self-identified as homebound rather than selecting them against my own definitions or criteria. This was in response to the wide range of definitions and measures used in the existing literature and the lack of previous conceptual investigation of the term. I understood homeboundness to be a complex, multi-faceted state with multiple definitions, causes, and trajectories, and I hoped to explore how homebound people defined themselves rather than relying on existing clinical definitions and service eligibility criteria.

I distributed study flyers and emails to a wide range of service providers, including various Meals on Wheels/food delivery organizations, home library services, religious organizations such as home ministry programs at churches and synagogues, home health agencies, aging support organizations such as Self Help for the Elderly, Openhouse, and local case management services, and a home-based primary care practice. Recruitment was more challenging than I had expected, particularly after the beginning of the COVID-19 pandemic. Most of the calls I received in response to my flyers were from clients of just one or two programs, some of whom were homebound and others not. Overall, I interviewed almost everyone who contacted me, and the sample was nonetheless smaller than I had anticipated and less diverse in terms of race, ethnicity, and age. I targeted my ongoing recruitment efforts more narrowly, reaching out to organizations serving specific racial/ethnic groups and neighborhoods and altering the eligibility criteria I shared with my contacts to focus on people of color, but I was not successful in expanding my sample.

I ceased recruitment once I felt I had achieved at least partial saturation, in the sense that analysis of the last few interviews had not generated substantial new codes or categories or changed the overall shape of the results. I expect that, had I been able to recruit a more diverse sample, particularly in terms of race, ethnicity, and age, I would have needed more data to reach saturation and would have produced more nuanced results reflecting wider experiences within the homebound population. However, as my attempts to recruit more participants continued without success, I decided in conjunction my research advisor that it was appropriate to stop data collection.

In a discussion of data saturation in grounded theory, Aldiabat and le Navenec (2018) explore multiple factors affecting decisions about saturation, including the research question and approach, homogeneity of the sample, expertise of the researcher, resources such as budget, time, and availability of participants, and target audience. They note that more studies with homogenous samples tend to reach saturation sooner, and that resource and time limitations associated with student research often shape decisions about saturation. Recent qualitative studies of experiences of homebound people have employed smaller or similar size samples to mine (Cheng et al., 2020, 2022; Liu et al., 2021; Mickler et al., 2021) presumably due to similar challenges with recruitment. In chapter 5, I recapitulate the limitations of my sampling and study design further, and I discuss the lessons I have learned for future study design.

For my third paper (chapter 4), I focused on experiences of homebound people during the COVID-19 pandemic. The pandemic was particularly challenging for the estimated two million homebound people in the US. Many of the clinical characteristics associated with being homebound are also risk factors for serious illness and death from COVID-19 infection. In addition, shelter-in-place and stay-at-home orders greatly increased demand for services such as grocery deliveries that many homebound people had previously relied on, and almost all home visiting services were suspended.

The pandemic significantly impacted my plans for this research study. I intended to complete all the interviews in person, in participants' homes. COVID made this impossible for an extended period of time, and it also fundamentally changed the experience of being homebound, the central focus of my work. After realizing that in-person visits would not be feasible for a long time, I moved to Zoom and telephone interviews, and I updated my interview guide to include questions about living through the pandemic (see Supplement).

Notes on Positionality and Reflexivity

I was aware throughout data collection and analysis of my positionality – participants frequently referred to my status as a "young" person, in contrast to what they saw as society's disregard for older people, they asked me for advice about their health and living situations, and many of them commented on the fact that I had moved to this country recently, typically assuming that I had a very limited understanding of health and social care provision in the US. Grenier (2007) identifies the relative lack of attention to age differentials within researcher-participant relationships compared to other social locations, arguing that qualitative interviews may present opportunities for older adults to respond to internalized ageism or to reimagine diminished identities. I was also conscious of my identity as a middle-class White woman with significant educational and other forms of privilege, which likely exacerbated the power differential inherent in the practice of most research but may also have facilitated my access to some participant groups. I was very aware of the imbalance created by entering participants' homes and asking them many personal questions about their lives when they knew little about me and my background, so I intended to be as open as possible. However, after several participants asked me about my family but then repeatedly misgendered my wife, and others made homophobic comments in response to the demographic questionnaire I used, I became somewhat more reticent.

In an attempt to explore how my position affected the ways in which participants described their experiences to me, as well as thinking through how these lenses influenced my construction of my findings, I worked on reflexive memoing, aiming to integrate these impressions into my analytic work rather than keeping them as separate processes. I also wrote notes before each interview on my expectations, noting how these were driven by my initial interactions by phone with participants as well as data points including the area where they lived and the organization through which they had received my recruitment materials. Several participants explained complex entry procedures I would need to follow to get into their buildings or advised me not to lock my bike outside because of high crime rates in the neighborhood, influencing my early impressions of them and their surroundings; I am conscious that my clinical experiences in home health likely amplified my tendency to anticipate what I might find when I visit someone for the first time.

It is impossible to be an “unbiased” or neutral qualitative researcher. Aspects of my positionality shape my assumptions and my relationships with participants, as well as informing my commitment to conducting research in this field. By interrogating, reflecting on, and acknowledging my identity and experiences, I hope to produce work with more nuance and value.

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Chapter 2 : A new conceptual model of experiences of aging in place in the United States: Results of a systematic review and meta-ethnography of qualitative studies

Abstract

Objectives: The purpose of this systematic review was to synthesize the evidence on experiences of aging in place in the United States.

Design: Systematic review and meta-ethnography of qualitative studies.

Data sources: We searched six bibliographic databases (PubMed, Embase, PsycINFO, CINAHL, Web of Science, Sociological Abstracts), with no limits on publication date. Eligible studies reported peer-reviewed qualitative research on experiences of aging in place in the United States with full-text available in English.

Review methods: Three reviewers independently used Covidence software to screen titles and abstracts followed by full texts. We assessed quality and risk of bias using a modified version of the Joanna Briggs Institute Checklist for Qualitative Research. Qualitative data analysis was conducted using meta-ethnography, following Noblit and Hare's seven-step method of translation and synthesis to generate a novel conceptual model.

Results: Of 2659 papers screened, 37 unique studies were eligible for inclusion, reported in 38 publications. The studies were conducted in 16 states and published between 1994 and 2018. The included samples represented 1199 participants in total, with mean ages ranging from 48 to 91 years. The gender of the samples ranged from 20% to 100% female, with a median of 77%. One-third of the included studies did not report participants' race/ethnicity, and half of the remaining study samples were at least

90% white; however, 20% of the studies focused exclusively on experiences of racial/ethnic minority older adults. Using meta-ethnography, we developed a new conceptual model of aging in place in the United States as a dynamic process of balancing threats and agency in relation to experiences of identity, connectedness, and place. We found that people aging in place were engaged in significant work to cope with unpredictable needs and challenges by changing their mindset, adapting their home environment to accommodate new needs, and finding different ways to connect with important people in their lives. Agency was shaped by resources and restrictions on choice, and where threats to aging in place outweighed an individual's sense of agency, the consequences included feelings of uncertainty, isolation, and dislocation. *Conclusions*: To the best of our knowledge, this is the first systematic review of qualitative studies to evaluate experiences of aging in place in the United States. The findings of our meta-ethnographic synthesis led to development of a new conceptual model of aging in place highlighting the dynamic tensions involved in balancing threats and agency.

Keywords

- Aging at home
- Aging in community
- Aging in place
- Conceptual framework
- Independent living
- Living alone

- Meta-ethnography
- Older adults
- Qualitative research
- Systematic review

Contribution of the paper

- What is already known about the topic?
    - The US population is aging, and the older adult population is becoming more diverse and experiencing a high burden of chronic disease.
    - Aging in place is typically a preferred option for older adults in the US, compared to institutional settings, although African Americans and lesbian, gay, bisexual, transgender, and queer (LGBTQ) older adults may feel less confident about their ability to age in place.
    - Only two systematic reviews specifically about aging in place have been published, both taking a narrow focus on the role of technologies, so a more comprehensive review of experiences of aging in place was indicated.
- What this paper adds
    - In the first systematic review and meta-ethnography on this topic, we found aging in place in the US to be an active, dynamic process

- Our novel dynamic tension model centers on experiences of identity, connectedness, and place, which are informed by the balance between threats and agency while aging in place
- We identified important gaps in the US literature, particularly in terms of the underrepresentation of geographic and racial/ethnic diversity

Introduction

Aging in place is an increasingly important concept globally. Around 9% of the world's population is over 65, and this age group is growing faster than all others worldwide (United Nations Department of Economic and Social Affairs Population Division, 2019). By 2030, it is projected that 23.5% of the population of the US will be over 65, compared to 14.5% in 2014 (Vespa et al., 2018). While the growth of the US population as a whole is likely to slow, it will continue to become both older and more diverse. As people live longer, they experience higher rates of chronic disease; in 2014, 81% of US adults aged 65 years or older reported multiple chronic conditions, compared to 42% of the general population (Buttorff et al., 2017). One response to the growing number of older adults in the US has been to encourage aging in place, which is seen as both cheaper and preferable to moving to an institutional setting in older age. Although there is no consensus on the exact meaning of aging in place, the definition used by the Centers for Disease Control and Prevention (2009) is often used: "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level." Policy initiatives aimed at supporting aging in place in the US include insurance coverage for home-based care and subsidies for home adaptation (Szanton et al., 2016). Such strategies are seen as cost-effective as the costs of residential care in the US continue to rise; in 2018 the median annual cost of a private room in a nursing home was $100,375, and 62% of nursing home residents are publicly funded through Medicaid (Kaiser Family Foundation, 2017).

Aging in place is not only popular with policymakers but also seems to be the preferred option among the general US population. In 2018, an American Association of

Retired Persons (AARP) survey found that 76% of people aged 50 or older would prefer to remain in their current home for as long as possible, and the number of people with this preference increased with age (American Association of Retired Persons, 2018). However, lesbian, gay, bisexual, and transgender older adults and African Americans were more likely to predict that they would move elsewhere in the future, perhaps reflecting unmet needs or different preferences for aging. Alternatives to aging in place for these groups may include moving in with family, shared housing, or institutional settings that are explicitly welcoming to them (American Association of Retired Persons, 2018); residential settings may feel more comfortable for people who would have increased access to social support there than at home. In their summary of theoretical perspectives, Scharlach and Moore (2016) call for research focusing on disparities in ability to achieve aging in place and exploring the diverse and dynamic nature of older adults' experiences, rather than accepting aging in place as “a single, universal goal” (p. 420).

A review of trends in publications about aging in place since 1980 traces a gradual increase in the number of papers published during the 1990s, followed by a sharp rise from 2000 onwards (Vasunilashorn et al., 2012). The authors also note the broadening range of topics covered, including health, technology, services, and environment, among others, as well as the diversity of aging-in-place populations considered in the literature. Over time, the proportion of research-based articles increased markedly compared to policy-based papers, perhaps suggesting that aging in place is now considered to be well established as a policy direction.

Despite the growing number of published papers on aging in place, only two systematic reviews specifically about aging in place have been published and neither explores the complexity and diversity of experiences of aging in place in the US (Graybill et al., 2014, Peek et al., 2014). In a systematic review of factors influencing acceptance of technology, including qualitative, quantitative, and mixed-methods studies, the authors identified six themes: concerns, expected benefits, needs, alternatives, social influences, and characteristics of people aging in place (Peek et al., 2014). Another systematic review of economic evaluations of aging in place suggested that assisted living technologies such as telemedicine and home modifications may be cost-effective (Graybill et al., 2014).

The close focus on technologies in existing systematic reviews in this field means they illuminate only one aspect of what it is like to age in place. In addition, these previous reviews include data from a range of countries around the world, making it difficult to separate the influence of country-specific differences in norms, policies, and service provision from variations in fundamental processes of aging in place. Therefore, a holistic review of the qualitative literature on aging in place is needed to shed light on lived experiences of aging in place for older adults in a range of different circumstances. To address these knowledge gaps, we aimed to conduct a systematic review and meta-ethnography of qualitative studies to synthesize the evidence on experiences of aging in place in the US. We focus exclusively on studies conducted in the US due to its particular demographic, structural, cultural, and political context.

Methods

Protocol and Registration

This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and checklist (Moher et al., 2009) as well as the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guideline (Tong et al., 2012) and the eMERGe guidance for reporting meta-ethnography (France et al., 2019). It is registered with the International Prospective Register of Systematic Reviews (PROSPERO), registration number CRD42018102847. A detailed description of the methods can be found in the published study protocol (Rosenwohl-Mack et al., 2018).

Synthesis Methodology

This synthesis of qualitative studies on aging in place in the US was conducted using meta-ethnography, following Noblit and Hare's seven-step method (Noblit and Hare, 1999, Rosenwohl-Mack et al., 2018). This interpretive approach was selected here due to its focus on generating new conceptual models to explain complex phenomena (Atkins et al., 2008). Meta-ethnography involves the extraction, analysis, and translation of first- and second-order constructs (Schutz, 1962) from included studies in order to form novel third-order constructs. First-order constructs are defined as direct quotations from participants in the included studies, second-order constructs are the original study authors' interpretations, and third-order constructs are new conceptual insights generated by the authors of the meta-ethnography.

Eligibility Criteria

Studies were eligible for inclusion if they met the following criteria: 1) qualitative research; 2) on the experiences of community-dwelling older adults aging in place; 3) conducted in the US; 4) published in English; and 5) in peer-reviewed publications. Those studies in which participants had already relocated or decided to relocate to institutional settings such as nursing homes or age-segregated supportive housing were excluded. For the purposes of this study, aging in place was defined as remaining in one’s familiar home or community until the end of life. This working definition was developed by reviewing institutional and theoretical definitions of aging in place, including those provided by the Centers for Disease Control and Prevention, American Association of Retired Persons (AARP), and the National Aging in Place Council. We considered studies to be about aging in place and therefore eligible for inclusion if they described aging in place as defined above in their introduction or results section. We did not impose any eligibility criteria related to participant age, since aging trajectories are highly individual and influenced by many factors beyond chronological age (Rosenwohl-Mack et al., 2018).

Information Sources and Search Strategy

A pre-planned systematic search strategy was developed in conjunction with a medical librarian for use with six electronic databases: PubMed, Embase, PsycINFO, CINAHL, Web of Science, and Sociological Abstracts (see Supplement for search details). A combination of MeSH/Emtree terms and keyword searches were used to identify studies on aging in place that met the inclusion criteria above, with the final searches completed in May 2018. No date limits were applied, to facilitate evaluation of how the concept of aging in place and interest in exploring it through qualitative research have developed over time.

Study Selection

All of the retrieved references were imported into Endnote reference management software (Clarivate Analytics, 2018), duplicates were removed, and then the remaining citations were imported into Covidence systematic review software (Veritas Health Innovation, 2013). In the first phase of screening, two researchers (AR-M and YF) independently assessed study titles and abstracts against the eligibility criteria. In the next stage, the remaining studies were read in full by AR-M and KS, with an agreement rate of 96.5%. Discrepancies at each stage were resolved through discussion with a third researcher (KS or YF).

Data Collection Process and Data Items

One researcher (AR-M) extracted information on each study's aims, sample characteristics, and methods, populating a table created in Microsoft Word. A second researcher (YF) checked the data extracted for a sample of the studies. AR-M also extracted second-order constructs, i.e., themes identified by the researchers from the results section of each study, alongside direct quotations from participants (first-order constructs), creating a second data table for use in the process of meta-ethnographic synthesis.

Quality Assessment and Risk of Bias

AR-M assessed the quality and risk of bias of each study using a modified version of the Joanna Briggs Institute Checklist for Qualitative Research (The Joanna Briggs Institute, 2017); two fields were added: relevance to the synthesis and overall quality assessment. The overall quality was rated as either key paper, satisfactory paper, irrelevant to the synthesis, or fatally flawed, following Dixon-Woods and colleagues (2007). The “key paper” designation referred to studies that demonstrated robust methods and focused specifically and primarily on aging in place. Irrelevant and fatally flawed studies would be excluded, all satisfactory papers would be included, and key papers would be given particular weight in the meta-ethnographic synthesis. KS and YF independently assessed the quality and risk of bias in a sample of five studies to confirm inter-rater agreement. The GRADE-CERQual approach (Lewin et al., 2015) was used to assess how much confidence should be placed in the conclusions of this systematic review, incorporating evaluation of methodological limitations, adequacy of the data presented, and the coherence and relevance of the findings.

Synthesis of Results

AR-M and KS worked closely together on the meta-ethnographic synthesis, using an iterative and inductive approach; YF provided feedback at each stage. AR-M created a translation table using Microsoft Word to group similar second-order constructs together and to compare these across studies, developing original third-order constructs to inform a new conceptual framework. We extracted second-order constructs from sets of five to ten studies at a time, allowing us to carefully compare each new set of constructs to our developing model and identify points of agreement as well as difference. Only themes and quotations reported in the results section of each study were included. Visual representations, reflective and analytic memos, and discussion of key dynamics and tensions in the data were used to refine the emerging model.

We used multiple strategies to maintain rigor and reduce bias, including the active participation of an experienced qualitative researcher in the analysis, sustained engagement and immersion in the data, and regular meetings of all three researchers to review emerging findings (Creswell, 2007, Tracy, 2010). We also explored our positionality as researchers and the potential impact of our experiences, assumptions, and biases on our data analysis through reflexive memos and discussion.

Results

Study Selection

Figure 2.1 summarizes the process of study selection. 37 unique studies were ultimately included in the meta-ethnographic synthesis.

Figure 2.1 PRISMA flow diagram of study selection and exclusion

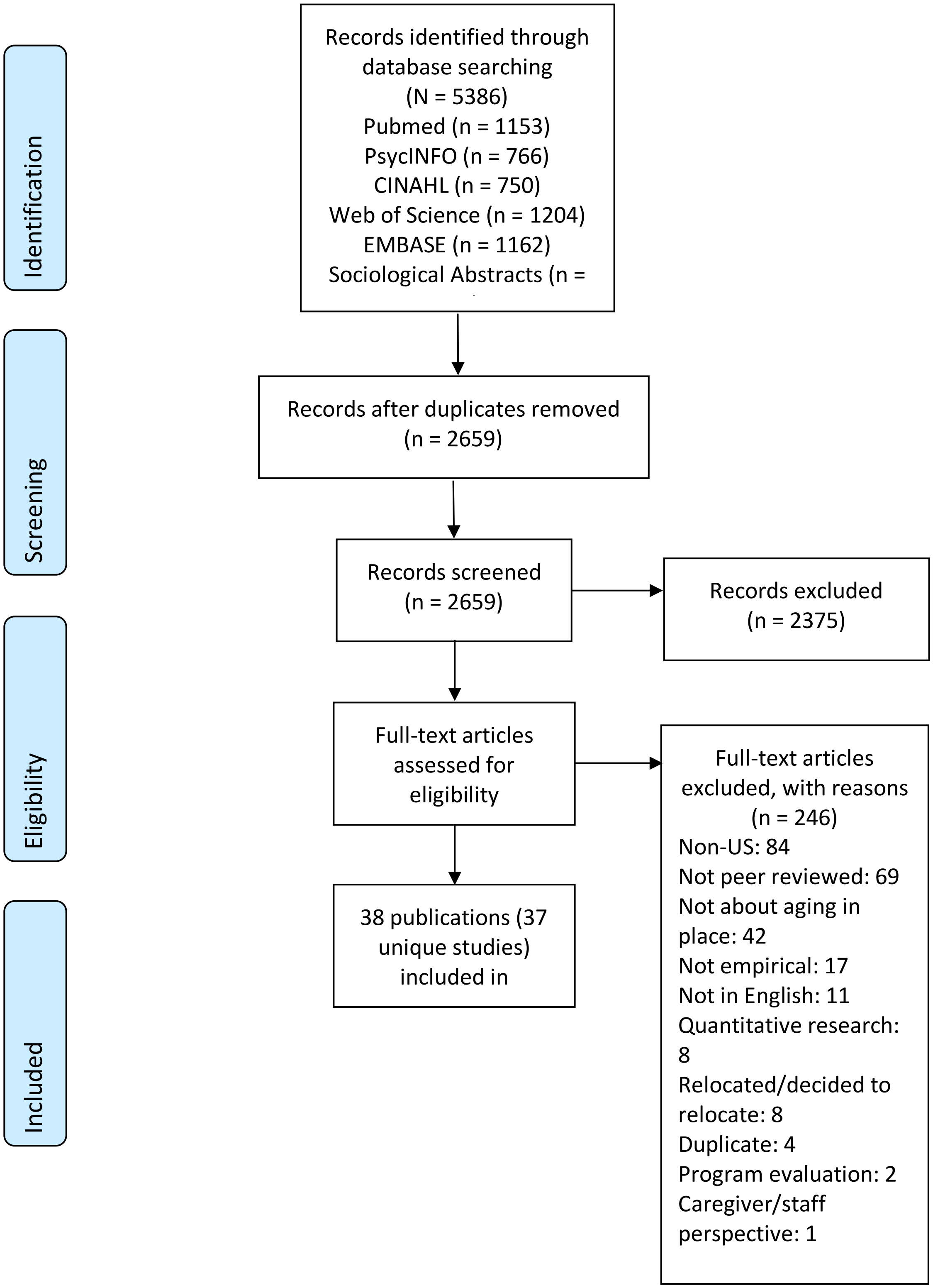

Table 2.1 Study and sample characteristics

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				**Gender**			**Employment status**	
1	Porter (1995), Porter (1994)	To describe older widows' experience of living at home alone	Interpretive paradigm of social gerontology (phenomenological sociology)	7	75-83	NR	NR	NR	100% living alone in own home
	NR[1]				100% female			NR	
2	Krothe (1997)	To understand the context within which designated elderly individuals would be able to continue residing in their communities	Constructivist paradigm	9	65-93, 81 (NR)	NR	NR	NR	6-72 years in present residence (mean 29)
	NR (Midwest)				78% female, 22% male			NR	
3	Porter (1998)	To describe older widows' intentions concerning their preferred future living arrangements	Descriptive phenomenology	16	75-84	100% "of European ancestry"	NR	NR	100% living alone in own home
	Missouri, Wisconsin				100% female			NR	
4	Swenson (1998)	Explored the meaning of home to women who were living in their own homes	Hermeneutic methods of analysis	5	75-87	NR	100% high school graduates	NR	100% living alone in rural town, in same house for over 30 years
	NR				100% female			NR	
5	Keigher (2000)	To identify and examine the "interests" of different stakeholders in care	NR	40[2]	80.3 (10.3)	32% black, others NR	NR	NR	38% living alone, 41% own their dwelling
	Wisconsin				65% female			NR	

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[1] Not reported

[2] Demographic information only available for 34 of the 40 participants

#	Author (year)	State	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Gender	Race/ ethnicity	Education	Annual income	Employment status	Living and housing situation
6	Roberts and Cleveland (2001)	Maine	To explore the life experiences of elder island women	Phenomenology	9	80-94	100% female	100% "Caucasian"	22% did not finish high school, 44% high school diploma, 33% one or more years education beyond 12th grade	NR	33% still working	100% living alone, 17 to 77 years in current residence
7	Rosel (2003)	Maine	Exploration of elders' personal knowledge of where and with whom they are aging in place	Phenomenology, narrative accounts	10	72-91	80% female, 20% male	NR	NR	NR	NR	100% homeowners, 24-72 years in current residence (mean 45)
8	Stevens-Ratchford and Diaz (2003)	District of Columbia	To examine aging in place in relation to occupation and successful aging	NR	4	65-77, 72.75 (NR)	100% female	75% African American, 25% Native American	50% graduated from college; 50% graduated high school and received some type of vocational training	NR	100% retired for at least one year	50% living alone
9	Hinck (2004)	Missouri	To describe life experiences of oldest-old individuals in the rural Midwest	Interpretive phenomenology	19	85-98, 90.7 (NR)	68% female, 32% male	100% white	NR	NR	NR	100% living alone in rural areas

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				**Gender**			**Employment status**	
10	Crist et al. (2006)	To explore Mexican American elders' use of home care services more comprehensively than previous research	Grounded theory	11	55-80	100% Mexican American	NR	NR	82% living with caregiver(s)
	NR (Southwest)				NR			NR	
11	Cook et al. (2007)	To gather baseline data on risk and resiliency factors in rural elderly persons	NR	42	Focus group means: 77.5; 91.2; 78; 88.5	100% white	NR	NR	60% rural, 40% urban
	Iowa				70% female (3 focus groups); 56% female (one focus group_			NR	
12	King and Dabelko-Schoeny (2009)	To understand the healthcare and social support experiences of midlife and older LGB adults living in rural areas and their perceptions of their ability to remain in their homes as they age	Qualitative grounded theory approach	20	40-75	5% biracial; 5% Hispanic; 90% white	NR	NR	NR
	US-wide				20% female; 80% male			NR	
13	Lewis (2009)	To illuminate the complex interplay of social structures and meanings and to offer insight on ways to better serve aging refugees and immigrants	Ethnography	38	NR	100% Cambodian (Khmer)	NR	NR	Rural location
	Alabama				NR			NR	

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
14	Birnholtz and Jones-Rounds (2010)	How seniors balance their desire for independence with the need to interact, and how caregivers and relatives help them do this	NR	11 seniors	74 (7.9)	NR	NR	NR	Area: combination of rural and small cities
	NR				27% male, 73% female			NR	
15	Heatwole Shank and Cutchin (2010)	Exploring how occupational engagement generates meaning	Multiple case study approach	3[3]	87-90	100% “Caucasian”	NR	NR	100% living alone, 54-58 years in current home
	North Carolina				100% female			NR	
16	Steggell et al. (2010)	To investigate the interests and concerns of USA minority elder women regarding the application of technology to support aging in place	NR	19 Korean	65-83	100% Korean	32% less than high school, 42% high school, 5% vocational school/ some college, 21% college graduate	69% =<$15,000, 11% $25,000-$49,000, 21% >=$50,000	16% living alone, years in US: <1 5%, 1-5 5%, 6-9 16%, >=10 73%
					100% female			NR	

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[3] Only two participants were aging in place; characteristics reported here are for those two only

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
	Oregon			13 Hispanic	62-73	100% Hispanic	85% less than high school, 15% high school	92% =<$15,000, 8% $25,000-49,000	100% living with others, years in US: <1 8%, 1-5 15%, 6-9 39%, >=10 39%
					100% female			NR	
17	Dye et al. (2011)	To elicit perspectives from rural residents regarding appropriate strategies, specifically the use of paraprofessionals [to facilitate aging in place]	NR	39	10.3% 60-64 years; 20.5% 65-69 years; 28.2% 70-74 years; 15.4% 75-79 years; 12.8% 80-84 years; 12.8% 85+ years	NR	33% high school diploma or less; 38.5% college degree	28.2% <$13,000; 12.8% $13,000-$18,999; 7.7% $19,000-$24,999; 17.9% $25,000-$44,999; 25.6% over $45,000	89.7% living in own home, 100% living in rural county; 7.7% living with family
	South Carolina				NR			NR	
18	Beard et al. (2012)	Compares how diagnosed individuals and those who care for them define AD and narrate their	Grounded theory	20 (10 couples)	50-89, 73 (NR)	80% Caucasian, 20% Hispanic	All had at least 12 years of schooling; 9 of	Median income $65,000-$99,999, one couple below $20,000	90% urban, 10% rural

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				**Gender**			**Employment status**	
	NR	subsequent experiences			50% female, 50% male		10 couples had at least some college	NR	
19	Kietzman et al. (2012)	To learn about the broader support network that IHSS care recipients avail themselves of to maintain their status of living independently in the community	NR	33	65-90, 75 (NR)	45.5% white, 30.3% Latino, 12.1% African American, 3% American Indian, 3% African American/American Indian; 3% Chinese; 3% Filipino[4]	58% more than high school; 15% high school graduate; 27% less than high school[5]	100% low income (Medicaid eligible)	NR
	California				79% female			NR	
20	Lau et al. (2012)	Describe the use of informal and formal support and explore perceived barriers to their use among community-dwelling Nikkei elders living alone	NR	34	78 (NR)	100% Japanese American	24% high school diploma or less, 34% some college, 27% college degree, 15% graduate/professional degree	19% less than $20,000; 15% $20,000-$30,000; 17% $30,001-$40,000; 20% 40,001-$50,000; 17% more than $50,000; no answer 12%	75% homeowners, 65% metropolitan area, 35% suburban
	Illinois				79% female, 21% male			NR	

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[4] Total 99.9% due to rounding

[5] Data only available for 26 of the 33 participants

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
21	Heinz et al. (2013)	To explore some of the greatest needs and challenges a diverse group of older adults believed they were facing or would face in the future	NR	30	83 (8.11)	96.7% white, 3.3% not reported	High school diploma 23.3%; some college 23.3%; college degree 23.3%; some postgraduate education 6.7%; graduate/professional degree 20%; missing data 3.3%	NR	3 focus groups: two recruited in university town, one in small rural community
	NR (Midwest)				60% female, 40% male			96.7% retired; 3.3% working part time	
22	Kohon and Carder (2014)	To learn how low-income older adults perceive their independence, health, and identity in relation to their place of residence	NR	47	69 (NR)	74% white/Caucasian, 11% Black/African American, 2% American Indian/ Alaska Native, 2% Asian, 6% multiracial, 4% no response[6]	NR	Average monthly income $938	100% living in city; subsidized housing 62%, waiting list 38%; average time in current housing 5 years
	Oregon				70% female; 30% male			NR	
23	Black et al. (2015)	To advance our understanding of older adults' perceptions and the broader contributions of community residents in affecting dignity and	Appreciative inquiry; participatory action research	267	65-98	91% Caucasian	57% college educated	Focus groups: 19% <$13,000, 23% $13,001-26,000, 19% $26,001-55,000, 39% >$55,000.	Focus groups: 68% living alone, 100% living in city

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[6] Total 99%, rounded percentages reported

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
		independence in everyday interactions with older adults							
								10% currently working	
	NR				75% female			E-survey: 6% <$13,000, 18% $13,001-26,000, 30% $26,001-55,000, 46% >$55,000	E-survey: 40% living alone, 100% living in city
								20% currently working	
24	Bowland (2015)	To learn about the traumatic experiences, current concerns, and internal/external resources of older African American female survivors of interpersonal trauma who lived in the community	Modified grounded theory	25	49-77, 60.9 (6.2)	100% African American	28% did not have a high school education; 40% attended college: 24% had degrees	68% income $5000-10,000; 28% income under $5,000	Mixed-age public housing in metropolitan area (3 high risks buildings on same block)
	Washington				100% female			56% not working or retired	
25	Lien et al. (2015)	To examine objective measures of accessibility in concordance	Mixed methods embedded approach	12	66-89	NR	NR	NR	58% single-family/detached house; 17% age-specific

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
	NR (Pacific Northwest)	with perceived usability of the home environment among older adults with functional limitations			42% male, 58% female			NR	housing; 25% custom/planned for age housing Years in current home: 33% 0-10, 25% 11-20, 42% 21+
26	White et al. (2015)	Provide insights into low SES older adults' experiences of health in and around the home	NR	8	69-86, 77.25 (5.78)	NR	NR	100% income of less than $20,000 a year	100% living alone; 50% urban, 50% rural; 63% apartment, 25% single-family house, 12% mobile home
	NR				100% female			100% retired	
27	Yamasaki (2015)	What impact do the collective faith-based stories of service, socialization, and support have on older adults aging in community in Kasson?	Asset-based community development approach to participatory research	27[7]	72-96, 84 (NR)	NR	NR	NR	NR
	Minnesota				NR			NR	
28	Bradford et al. (2016)	To identify factors that facilitate or pose barriers to older lesbians' healthy aging and to gain insights into their needs and preferences for where and how they hope to live as they age	NR	26	64-71, 68 (NR)	100% white non-Hispanic	NR	Median income $50,001-$70,000.	36% living alone ; 52% single family home; 48% apartment, condo, or room in building open to people of all ages. 54% rural, 46% urban
	Massachusetts				100% female			54% retired	
29	Dobner et al. (2016)	What are the experiences of formal and informal social support and	Comparative case study with multiple (within-case) observations	27[8]	65-94, 73 (NR)	NR	NR	NR	30% living alone

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[7] 7 living in assisted living but demographic data only provided for combined sample

[8] All sample demographics only reported for whole sample, including Dutch case study

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
	Oregon	neighborhood ties of older adults ageing in place in Amsterdam and Portland?			63% female, 37% male			NR	
30	Heatwole Shank and Cutchin (2016)	To develop a grounded theory of community livability for older adults, specifically attending to the relationship of older adults and the physical and social environments through which daily activities unfold	Grounded theory; instrumental multiple case study design	12	71-99, 78 (NR)	33% African American, 67% Caucasian	25% less than high school	NR	50% living alone, 17% living with full-time caregivers Average time in current residence 46 years 58% detached house; 25% apartment; 17% duplex
	North Carolina				67% female; 33% male			33% working part time; 67% not working	
31	Lindquist et al. (2016)	To explore what older adults perceived would affect their ability to remain in their own home and how they had planned for these potential events	NR	68	73.8 (6.5)	NR	8.8% some high school, 14.7% high school graduate, 26.5% some college, 19.1% college graduate, 25% some postgraduate education	NR	70.6% apartment/house/condo, 8.8% retirement community, 16.2% other, 4.4% did not respond 70.6% urban, 17.6% suburban, 5.9% rural, did not respond 5.9%
	Illinois, Indiana				72.1% female			8.38% retired, 4.4% working, 2.9% unemployed/looking for work, 4.4% other, 4.4% did not respond	
32	Portacolone and Halpern (2016)	In-depth analysis of the composite dynamics behind the increasing segregation of older	Micro/subjective, meso/institutional, and macro/ideological lens of analysis	47[9]	NR (all over 75)	63% white, 8% Asian, 21% Black, 8% Latino	NR	NR	100% living alone
	California				71% female, 29% male			NR	

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[9] Only the 24 participants living in conventional housing were included in this systematic review

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				Gender			Employment status	
		Americans living alone							
33	Powell (2016)	To better understand the lived experiences of persons who share a campus-adjacent neighborhood	NR	71[10]	Interviews: 62.38 (NR)[11]	Interviews: 82% white, 18% non-white[12]	NR	NR	Interviews: Mean years of house/apartment tenure = 31.42[13] Mean years of neighborhood tenure = 34.36
					Interviews: 50% female, 50% male[14]			NR	
	NR				Focus groups: 62.5 (NR)	Focus groups: 63% white, 37% non-white	NR	NR	Focus groups: Mean years of house/apartment tenure = 33.93 Mean years of neighborhood tenure = 33.93
					Focus groups: 79% female, 21% male			NR	
					Photovoice: 48 (NR)	Photovoice: 100% white	NR	NR	Photovoice: Mean years of house/apartment tenure = 26.79 Mean years of neighborhood tenure = 32.38
					Photovoice: 38% female, 62% male			NR	
34	Boggs et al. (2017)	To assess the perceptions of urban-dwelling LGBTQ older adults on aging in place to	NR	73 (intercept survey 17, focus	40-79	26% white, 3% Hispanic, 3% African	NR	NR	45% living alone; 66% house, 34% apartment/condo/townhome; mean

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[10] Also includes students, landlords, and officials, whose results were not included in the systematic review.

[11] Age data includes year-round residents only

[12] Race/ethnicity data includes all groups

[13] Tenure data includes year-round residents only

[14] Gender data includes all groups

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				**Gender**			**Employment status**	
	Colorado	inform the development and implementation of an aging in place model		group 14, town hall 30, final interview 12)[15]	69% female, 31% male, 7% transgender[16]	American; 62% not reported		NR	years at current address 18 (sd 14)
35	Butler (2017)	To respond to the question of whether the phenomenon of nearly all home care workers being women mitigates potential tensions for older lesbians using home care services Gaining an understanding of the relationship between the lesbian receiving services and the home care workers delivering those services	NR	20	66-86, 71.9 (NR)	100% white	70% had received a graduate degree	25% under $20,000, 35% $20,000-$40,000, 30% $40,000-$60,000, 10% over $80,000	NR
	Nation-wide				100% female			NR	
36	Li et al. (2017)	To understand older Chinese immigrants' experiences of aging in the United States	NR	24	65-92, 77.38 (NR)	Self-identity: 12.5% American, 37.5% Chinese, 41.7% Chines	45.9% lower than high school, 20.8% high school, 33.4% higher	NR	37.5% living alone, mean years in United States = 21.87 (sd 12.79)

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[15] Demographic data only available for individual interviews

[16] Participants could choose more than one response

#	Author (year)	Primary aim	Methodological approach	Sample size	Age range or mean (sd)	Race/ethnicity	Education	Annual income	Living and housing situation
	State				**Gender**			**Employment status**	
	California				54.2% female, 45.8% male	e American, 8.3% Chinese and American	than high school	25% working, 75% not working	
37	Yuan et al. (2018)	What are the activities that older adults coproduce with one another and the hindrances for doing them? How can our findings shed lights on technology designs to facilitate and support diverse coproductions?	NR	13	59-95[17]	NR	NR	NR	College town
	NR (Northeastern US)				31% male, 69% female			NR	

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[17] Includes continuing-care retirement community residents

Study and sample characteristics

Summary of Study Designs and Sample Characteristics

Table 2.1 provides details of the characteristics of each study and sample. 1199 participants were represented in the included studies, with sample sizes ranging from 3 to 267 participants. The mean ages of the samples ranged from 48 to 91 years, and gender was 20 to 100% female, with a median of 77% female. 11% of the studies sampled only lesbian, gay, bisexual, or transgender older adults (Boggs et al., 2017, Bradford et al., 2016, Butler, 2017, King and Dabelko-Schoeny, 2009), but no other studies reported the sexual orientation of their participants.

The included studies were conducted in 16 states. Participants' race/ethnicity was not reported in one third of the studies, and for half of those that did report race/ethnicity the samples were at least 90% white. 20% of the included studies sampled only people of color, with five studies focusing specifically on experiences of immigrant elders, including Mexican American (Crist et al., 2006), Japanese American (Lau et al., 2012), Cambodian refugees (Lewis, 2009), Chinese (Li et al., 2017), and Korean and Hispanic older adults (Steggell et al., 2010).

Of those studies that reported information on participants' living situation, eight study samples (22%) consisted entirely of people living alone. The data presented on housing situation were varied, including information on home ownership, years living in current home, years living in the US, rural vs. urban settings, and type of building, including subsidized or public housing. Seven studies (19%) focused explicitly on people living in rural areas, although "rural" was typically not defined, and six studies (16%) drew from predominantly urban populations.

In terms of socio-economic status, 15 of the 37 included studies (41%) reported education level and 10 studies (27%) reported income. Eight studies (22%) reported that their sample included some participants who had not finished high school, and four studies (11%) focused specifically on experiences of low-income older adults (Bowland, 2015, Kietzman et al., 2012, Kohon and Carder, 2014, White et al., 2015). It is difficult to summarize the income data provided in the included studies since the categories used vary widely, and median national income for older adults in the US depends on retirement status, which was not consistently reported alongside income data in these studies.

Five papers (representing four unique studies) were published in the 1990s, nine in the 2000s, and 24 since 2010. In 16 papers (43%), the authors provided an explicit definition of aging in place in the introduction or methods section. The most frequently used methodological approach was grounded theory (27%); others included content analysis (19%), phenomenology (14%), and thematic analysis (11%). Eight studies (22%) used focus groups for data collection, while all of the others used interviews, and several obtained additional data using photo elicitation and observation.

Quality Assessment

The results of the risk of bias assessment using the modified checklist are summarized in Table 2.2. In more than half of the papers assessed, the philosophical perspective underpinning the research was not stated, so it was not possible to assess congruity between the research philosophy and the methodology. No studies raised concerns about unethical research conduct, but in almost half of the papers there was no evidence of formal ethical approval having been granted. The other major area of omission related to reflexivity; only 10 studies (27%) included a statement locating the researcher culturally or theoretically, and in just 11 studies (30%) was there acknowledgement of the influence of the researcher on the research and vice versa.

In spite of these concerns, all of the included studies were judged to be of satisfactory quality due to their use of appropriate research methods overall and presentation of sufficiently rich data, and so all were incorporated into the meta-ethnographic synthesis.

As outlined in our CERQUal Evidence Profile for this systematic review (see Supplement), we assessed confidence in our review findings as moderate for four findings and high for eight findings. The primary concerns affecting confidence in our results relate to the absence of reporting on positionality and reflexivity in many of the included studies, as well as the fact that some findings were supported by a smaller number of studies than others.

Table 2.2 Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research, adapted (The Joanna Briggs Institute, 2017)

Study number	Congruity between stated philosophical perspective and research methodology?[18]	Congruity between research methodology and research question or objectives?	Congruity between research methodology and methods used to collect data?	Congruity between research methodology and representation and analysis of data?	Congruity between research methodology and interpretation of results?	Statement locating the researcher culturally or theoretically?	Influence of researcher on the research, and vice- versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria? Evidence of ethical approval by appropriate body?	Do conclusions drawn flow from the analysis, or interpretation, of the data?	Is it relevant to the synthesis?	Overall appraisal[19]
1	✓	✓	✓	✓	✓	✓	✗	✓	?[20]	✓	✓	SAT
2	✓	✓	✓	✓	✓	✗	✓	✓	?	✓	✓	SAT
3	✓	✓	✓	✓	✓	✗	✗	✓	?	✓	✓	SAT
4	✓	✓	✓	✓	✓	✗	✗	✓	?	✓	✓	SAT
5	?	✓	✓	?	✓	✗	✗	✓	?	✓	✓	SAT
6	?	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	SAT
7	✓	✓	✓	?[21]	✓	✗	✗	✓	?	✓	✓	SAT
8	?	✓	✓	✓	✓	✗	✓	✓	?	✓	✓	SAT
9	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓	SAT
10	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓	SAT
11	?	✓	✓	✓	✓	✗	✗	✓	?	✓	✓	SAT
12	?	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓	KP

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[18] Response options: yes ✓ ; no ✗ ; unclear ?;

[19] KP = key paper; SAT = satisfactory; FF = fatally flawed

[20] This question marked "unclear" if no formal ethical approval reported but no ethical concerns identified

[21] Methodology unclear

Study number	Congruity between stated philosophical perspective and research methodology?[18]	Congruity between research methodology and research question or objectives?	Congruity between research methodology and methods used to collect data?	Congruity between research methodology and representation and analysis of data?	Congruity between research methodology and interpretation of results?	Statement locating the researcher culturally or theoretically?	Influence of researcher on the research, and vice- versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria? Evidence of ethical approval by appropriate body?	Do conclusions drawn flow from the analysis, or interpretation, of the data?	Is it relevant to the synthesis?	Overall appraisal[19]
13	✓	✓	✓	✓	✓	✓	☒	✓	?	✓	✓	KP
14	?	✓	✓	✓	✓	☒	☒	✓	?	✓	✓	SAT
15	✓	✓	✓	✓	✓	☒	✓	✓	✓	✓	✓	SAT
16	?	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	SAT
17	?	✓	✓	✓	✓	✓	☒	✓	✓	☒	✓	SAT
18	✓	✓	✓	✓	✓	☒	☒	✓	✓	✓	✓	SAT
19	?	✓	✓	✓	✓	☒	☒	✓	✓	✓	✓	SAT
20	?	✓	✓	✓	✓	✓	☒	✓	✓	✓	✓	SAT
21	?	✓	✓	✓	✓	✓	☒	✓	✓	✓	✓	SAT
22	?	✓	✓	✓	✓	☒	☒	✓	✓	✓	✓	SAT
23	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	SAT
24	✓	✓	✓	✓	✓	☒	☒	✓	✓	✓	✓	KP
25	?	✓	✓	✓	✓	☒	☒	✓	✓	✓	✓	SAT
26	?	✓	✓	✓	✓	☒	☒	?[22]	?	✓	✓	SAT
27	✓	✓	✓	✓	✓	☒	✓	✓	✓	✓	✓	SAT

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[22] Unfamiliar research tradition – difficult to assess

Study number	Congruity between stated philosophical perspective and research methodology?[18]	Congruity between research methodology and research question or objectives?	Congruity between research methodology and methods used to collect data?	Congruity between research methodology and representation and analysis of data?	Congruity between research methodology and interpretation of results?	Statement locating the researcher culturally or theoretically?	Influence of researcher on the research, and vice- versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria? Evidence of ethical approval by appropriate body?	Do conclusions drawn flow from the analysis, or interpretation, of the data?	Is it relevant to the synthesis?	Overall appraisal[19]
28	?	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	SAT
29	?	✓	✓	✓	✓	✗	✗	✓	?	✓	✓	SAT
30	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓	SAT
31	?	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	SAT
32	?	✓	✓	✓	✓	✗	✗	✓	?	✓	✓	SAT
33	?	✓	✓	✓	✓	✗	✗	✓	✓	✓	✓	SAT
34	?	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	KP
35	?	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	SAT
36	?	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	KP
37	?	✓	✓	✓	✓	✗	✓	✓	?	✓	✓	SAT

Meta-Ethnography Results

Figure 2.2 provides a visual summary of the key constructs in the model of aging in place generated by our meta-ethnographic synthesis. Table 2.3 displays the relevant first-, second-, and third-order constructs. We found aging in place to be an active, dynamic process, in which experiences are informed by the balance between threats and agency (Table 2.3). Older adults have to deal with unpredictable threats to three interconnected core experiences of aging in place: identity as an older adult, connectedness with others, and sense of place. The capacity to respond to these threats and maintain important elements of their daily lives while aging in place is conceptualized as agency in this model. A few fortunate or resource-rich older adults aging in place experienced high levels of agency and were able to achieve their preferences across all three of the core experiences: identity, place, and connectedness. Many others had to negotiate, reprioritize, and sacrifice important aspects of their lives in order to sustain aging in place. For those in inappropriate or unsafe housing, continuing to age in place was not a choice – if they could, they would have moved elsewhere. As such, it is important to understand experiences of aging in place within the context of older adults' ability to choose between alternative options in response to specific threats to their experiences.

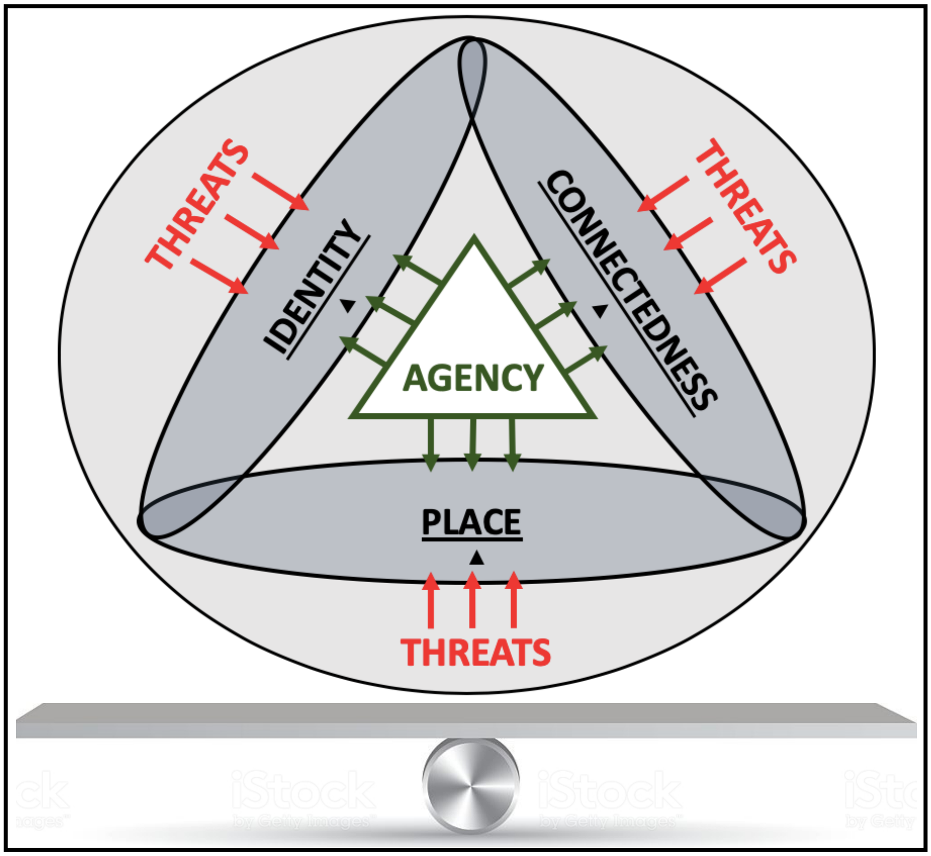

Figure 2.2 Conceptual model: Dynamic Tension Model of Aging in Place

Agency

“Agency” is defined in this model as the capacity of older adults to make choices about their lives, regarding both the overarching question of whether to age in place or move to a supportive institutional setting, as well as everyday choices about what aging in place looks and feels like in practice. The balance between resources available to each individual and restrictions on their ability to make choices determined the level of agency they experienced in relation to aging in place. Important resources for people aging in place included personal financial stability, social connections, and local services. The use of these resources was restricted by financial constraints, discrimination, lack of information, and cultural or language barriers. Reluctance to burden family members also limited the options available to people aging in place. When their level of perceived agency was outweighed by the threats they were facing, people aging in place were left feeling insecure or stuck, with limited options. For these older adults, a lack of agency over their circumstances resulted in a significant gap between their ideals or preferences for aging in place and the reality of their lived experiences.

Identity as an older adult

"Identity" within this conceptual model relates to a person's sense of self as they age in place, particularly in terms of their perceived independence and competence and their changing social roles. Threats to identity included experiencing changes in their health and function and needing assistance with everyday activities. For some, such changes were less distressing as they could be integrated in their overall sense of being an older person and transitioning into a different stage of life, particularly for those who felt part of a strong community, However, for others the loss of valued roles and responsibilities undermined or destabilized their self-image. Agency is closely related to identity for people aging in place, since experiencing reduced control over one's circumstances can trigger feelings of dependence and vulnerability.

Maintaining a positive sense of identity while aging in place. On the individual level, people aging in place focused on preserving and celebrating their independence and freedom, particularly for those living alone (Dye et al., 2011, Hinck, 2004, Keigher, 2000, Krothe, 1997, Li et al., 2017, Porter, 1995, Porter, 1994). Similarly, feeling competent and having a sense of purpose helped people aging in place to maintain a positive sense of self (Black et al., 2015, Heatwole Shank and Cutchin, 2016). At the level of the wider community, cultural influences on self-image were important, including feeling respected as part of a group of survivors, having shared experiences with peers, and drawing on advice passed on from community elders (Black et al., 2015, Krothe, 1997, Powell, 2016).

Threats to identity while aging in place. Health challenges and changes to functional abilities constituted particularly important threats to older adults' sense of self while aging in place, since they could force people to give up valued activities and routines (Black et al., 2015, Crist et al., 2006, Kietzman et al., 2012, Lindquist et al., 2016, Porter, 1998, Stevens-Ratchford and Diaz, 2003, White et al., 2015). The example of driving came up frequently, since it was associated with both a literal and a more figurative sense of independence (Black et al., 2015, Cook et al., 2007, Dye et al., 2011, Heinz et al., 2013, Lewis, 2009, Lindquist et al., 2016, White et al., 2015), and home upkeep was also a particular concern (Black et al., 2015, Heinz et al., 2013, Lindquist et al., 2016). Needing help from others could provoke feelings of vulnerability and dependence, as well as fears of discrimination, especially for LGBTQ people aging in place (Butler, 2017, King and Dabelko-Schoeny, 2009).

Asserting agency in response to threatened identity. People aging in place responded to threats to identity by focusing on preserved strengths, adapting valued routines, and taking control of their care needs (Keigher, 2000, Krothe, 1997, Lien et al., 2015, Porter, 1995, Porter, 1994, White et al., 2015). Comparing themselves to others could help people aging in place to focus on their strengths (Heinz et al., 2013, Hinck, 2004, Kohon and Carder, 2014, Krothe, 1997, White et al., 2015), and reflecting on their individual and cultural philosophies on life helped them to accept the changes they were experiencing (Hinck, 2004, Krothe, 1997). Some of those who had to accept outside help could assert agency over their situation by taking on the role of “manager” of their care needs (Crist et al., 2006, Keigher, 2000, Krothe, 1997). However, limited resources and fear of discrimination meant that not all people aging in place had sufficient agency to pursue these strategies.

Consequences of unmitigated threats to identity while aging in place. When threats to identity outweighed agency, the consequences included uncertainty, isolation, and avoidance of care, particularly for people who felt that the reality of their situation did not match what they’d hoped for in older age. In addition, those who did accept care but were not able to access sufficient or appropriate support reported unmet needs and experiences of poor care (Butler, 2017, Kietzman et al., 2012, Krothe, 1997).

Connectedness

“Connectedness” in the context of aging in place was experienced through in-person socialization, longer-distance connections, and use of technology. Social interactions shaped older adults’ sense of being connected to others on an individual level, as well as informing their impressions of how welcoming or hostile their wider community was. Taken as a whole, experiences of connectedness in aging in place were particularly varied, perhaps relating to differences in lifelong preferences for social contact. In turn, the potential threats to preferred connectedness ranged from discrimination and isolation to excessive or unwanted contact from family members, and strategies to address such threats included paying for help at home or choosing technology over human assistance. Connectedness informed sense of agency for people aging in place, since social connections could constitute resources to be deployed in the face of threats, although they could also be restrictive, particularly in the context of challenging dynamics with family and friends.

Maintaining a positive sense of connectedness while aging in place. Examples of sustained social connections for people aging in place were typically associated with having lived in the same place for a long time, particularly in rural areas (Heatwole Shank and Cutchin, 2010, Roberts and Cleveland, 2001, Rosel, 2003). For those who were familiar with the wider community, simply seeing people at a distance from a window or porch could evoke a sense of involvement (Birnholtz and Jones-Rounds, 2010, Krothe, 1997, Rosel, 2003, Swenson, 1998). Religious communities, senior centers, and technology could also facilitate connectedness (Birnholtz and Jones-Rounds, 2010, Li et al., 2017, Rosel, 2003, Steggell et al., 2010, Yamasaki, 2015). Reciprocal connections with others were especially valued (Heatwole Shank and Cutchin, 2010, Hinck, 2004, Kohon and Carder, 2014, Roberts and Cleveland, 2001, Stevens-Ratchford and Diaz, 2003, Yamasaki, 2015), and “neighboring” was a specific manifestation of this, involving feeling protected as well as proud to be able to support others. On a broader scale, volunteering and community organizing demonstrated connectedness as well as a sense of purpose and altruism (Black et al., 2015, Dobner et al., 2016).

Threats to connectedness while aging in place. Threats to connectedness for those aging in place included changes to a familiar neighborhood environment, functional impairment and increased care needs, and challenges in family relationships, as well as experiences of trauma and discrimination. Technology could also pose a threat to preferred forms of connection, leaving older adults afraid of being left behind or isolated and wary of the intrusion of surveillance into their private space, although some people aging in place tolerated frustrations with technology because they were preferable to having people come into their home. Older adults with increased needs for social support were at particular risk of threats to connectedness; these included trauma survivors living in low-income housing (Bowland, 2015), those who felt the state would not support them (Dobner et al., 2016), rural elders (Dye et al., 2011, Hinck, 2004), people with disabilities (Keigher, 2000, Kietzman et al., 2012), and LGBTQ older adults, who were conscious of not having children to help them (Boggs et al., 2017). Racism and discrimination related to sexual orientation or HIV status could also undermine connections with others.

Threats to connectedness were closely linked to identity for people aging in place, since relationships with others often affected individuals' sense of their roles and purpose in society. Feeling unable to "give back" for help received was a frustrating experience that affected older adults' perception of their value within their community (Heinz et al., 2013, Lau et al., 2012, Lewis, 2009, Li et al., 2017). A specific manifestation of this was seen in family relations, where older adults accustomed to having authority and independence within the family struggled to accept help from younger relatives (Lau et al., 2012, Porter, 1995, Porter, 1994), particularly when the help offered was experienced as overbearing or controlling (Krothe, 1997). Some older adults felt forced to choose between family and friend connections (Cook et al., 2007), and others tried to preserve familiar roles even when family members became caregivers to them. For low-income disabled older adults, Kietzman et al. (2012) found family caregivers to be “a critical component of the consumer network” (p. 329), although their ability to help could be limited by their other obligations.

Asserting agency in response to threatened connectedness. Community-level approaches to threats to connectedness while aging in place focused on building community infrastructure. For example, LGBT older adults fearing marginalization expressed a need to “build community before we desperately need it in our old age” (Bradford et al., 2016) (p. 111). On a more personal level, many older adults currently aging in place felt strongly that they would never want to live with their family, preferring to move to an institutional setting in the future rather than impose themselves and disrupt family life. Technology could allow people aging in place to maintain desired levels of connection while avoiding excessive in-person intrusion into their home.

In some cases, experiences of trauma and discrimination made people aging in place actively avoid social interactions in order to protect themselves. Some study authors found that the ability to avoid social time was a benefit of aging in place (Birnholtz and Jones-Rounds, 2010), particularly compared to the nursing home environment (Krothe, 1997, Stevens-Ratchford and Diaz, 2003). In challenging living situations, being able to set boundaries and choose when to interact with others was associated with a sense of agency and control while aging in place.

Consequences of unmitigated threats to connectedness while aging in place. Undesired isolation and a lack of social stimulation were the most significant consequences of unmitigated threats to connectedness among people aging in place.

This included isolation due to homophobia, xenophobia, or not having people “like you” nearby (King and Dabelko-Schoeny, 2009). These experiences were widespread in studies of immigrants “aging out of place,” including Japanese American elders living alone (Lau et al., 2012), Cambodian refugees (Lewis, 2009), and older Chinese immigrants experiencing language barriers, who connected their loneliness to American culture: “In this place [the United States], people don’t hang out with each other often.” (Li et al., 2017) (p. 4). Two studies of disabled elders’ care needs found desire for social time was often a neglected element of formal caregiving (Keigher, 2000), particularly for low-income older adults (Kietzman et al., 2012).

Place

The experience of ‘place’ while aging in place occurred at multiple levels, from the home to the neighborhood and even at the national level, for those who had moved to the US from elsewhere in the world. The personal and private nature of the immediate home environment was highly valued but potentially threatened by changes to health and functional ability. For some people aging in place, getting older meant having to accept intrusion into their private space and routines, and for those who feared discrimination or abuse the semi-public spaces of shared corridors or elevators could feel threatening and even dangerous. The sense of familiarity and continuity of place often implied in descriptions of aging in place was absent for some older adults and experienced as negative for others, particularly those whose past trauma was triggered by the place where they were living or who were desperate to be able to move elsewhere but felt stuck in place. Agency was key in determining whether place was experienced as choosing to remain in a positive, familiar setting or being trapped in an unsuitable and undesirable environment.

Maintaining a positive sense of place while aging in place. Many studies found the home to be a deeply personal space, shaped by years of construction as well as collecting valued items – this sense of maintaining connection to the physical home space was seen as a crucial benefit of aging in place (Hinck, 2004, Lindquist et al., 2016, Rosel, 2003, Stevens-Ratchford and Diaz, 2003, Swenson, 1998). The home had often been both physically and metaphorically constructed over the years, with some older adults having built their home from scratch or having made modifications to its structures, and others describing how they had filled their home with personally meaningful items: “This house is full of me” (Rosel, 2003) (p. 80). A study of Cambodian refugee elders found some had been able to build their own village, identifying the theme of “*home* and *place* as consisting of physical, sociocultural, and emotional environments” (Lewis, 2009) (p. 388). Home was also associated with maintaining privacy and control over one’s life (Krothe, 1997, Lien et al., 2015), as well as treasured occupations and activities (Heatwole Shank and Cutchin, 2010, Stevens-Ratchford and Diaz, 2003, Swenson, 1998). Beyond the immediate home space, familiarity of place extended to local buildings and natural space for those who had lived in the same place for a long time (Hinck, 2004).

Threats to place while aging in place. Although the personal home space was often treasured, it could also become a burden. The home environment could reveal participants’ functional struggles and disrupt social connections by prompting family members to try to intervene, whereas home upkeep had previously been a source of pride and self-reliance (Cook et al., 2007). Needing external help risked disrupting the home space, transforming personal items from treasured “companions” to markers of identities that put their owners at risk of discrimination and making the home feel like a workplace rather than a private space, particularly for LGBTQ older adults (Bradford et al., 2016, Butler, 2017). For those aging in place in challenging settings, the boundary spaces between private and public space constituted a particular threat to their wellbeing, in terms of potential violence and discrimination (Boggs et al., 2017, Bowland, 2015, Kohon and Carder, 2014). The threat of harm was especially prominent for marginalized older adults and those living in public housing, compounded by the fact that these older adults typically did not have the resources to move elsewhere.

On the neighborhood level, concerns about local physical infrastructure were a recurrent theme since they could render valued aspects of place inaccessible, particularly in terms of walkability (Black et al., 2015, Dobner et al., 2016, Dye et al., 2011) and transportation (Black et al., 2015, Heinz et al., 2013, King and Dabelko-Schoeny, 2009, Lien et al., 2015, Lindquist et al., 2016, Roberts and Cleveland, 2001, White et al., 2015). Being older and spending more time at home could transform the experience or perception of the neighborhood; for example, living in an area with many young families could become a lonely experience for an older adult, since their neighbors were usually elsewhere during the day, and changes in land use and local demographics could also be alienating and unsettling (Cook et al., 2007).

Asserting agency in response to threatened sense of place. People experiencing threats to their sense of place asserted agency by making changes to their environment. Within the home, these included significant remodeling to kitchens and bathrooms as well as simple reorganization to facilitate daily routines (Lien et al., 2015). Community organizing and efforts to promote infrastructure building could change the nature of place in a broader sense (Dobner et al., 2016), and one study of Cambodian refugees found they were able to find meaning in place by recreating Cambodian village life (Lewis, 2009).

Consequences of unmitigated threats to place while aging in place. When threats to place could not be managed, older adults experienced place as unfamiliar, unsafe, or no longer private. LGBTQ older adults fearing discrimination were forced to hide important items marking their identity in order to “de-gay” their homes before paid helpers came in, in a demonstration of the interconnectedness of identities, connectedness, and place for people aging in place (Bradford et al., 2016, Butler, 2017). In a study of African American trauma survivors living in low-income housing, Bowland (2015) described the communal spaces as feeling unsafe for participants, due to experiences of harassment, traumatic stress, and witnessing violence and death, as well as the potential for addiction to be triggered by others’ smoking, drinking, and drug use. Aging in place in public housing meant being exposed to surveillance and excessive intervention from the state, as well as a sense that other residents were watching and making assumptions about who was visiting them (Kohon and Carder, 2014). These examples demonstrate the intersection of place, connectedness, and identity for people aging in place: experiences of discrimination and marginalization throughout the life course were exacerbated as people became more dependent on their home environment and less able to resist negative external forces.

Table 2.3 Meta-ethnography translation

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
Agency	Choices	Thinking about future choices	“I don’t want to institutionalize myself unless it is absolutely necessary, but I’ll have sense enough to know if I can’t do it anymore.” (Krothe, 1997) (p.221)	2, 3, 5, 8, 12, 23, 31
		Having few options	“I can't find another place that's affordable, so I'm like a captive. I really feel trapped.” (Kohon and Carder, 2014) (p. 50)	12, 19, 22, 26, 31
	Resources and restrictions	Availability and appropriateness of local services and resources	“Right now, the only option, if you are in pretty bad shape, is to call 911. That is kind of an extreme.’’ (Dye et al., 2011) (p. 85) “Living in the suburbs, I have little association with other Nikkei. Everything I do is with Caucasians (hakujin)...There are no [adult day care or cultural activities for Nikkei] out there.” (Lau et al., 2012) (p. 157)	2, 6, 12, 17, 19, 20, 21, 23, 26, 27, 28, 29, 34, 35, 36, 37
		Financial restrictions	“I have expensive health insurance with a very high deductible. Therefore, I avoid [the] doctor except when absolutely necessary.” (King and Dabelko-Schoeny, 2009) (p. 18)	5, 12, 17, 19, 22, 26, 31, 35, 36
		Lack of information	“I have found a lot of information that I have also passed on to others . . . you’ll be surprised on what’s available to you, but you got to get out there and ask for it.” (Black et al., 2015) (p. 234)	2, 23, 31, 36
		Not wanting to burden others	“My children should have their own life,” […] “I don’t think it’s sensible for an older person to bunk up on their kids . . . it spoils their life.” (Krothe, 1997) (p. 221)	2, 3, 4, 9, 16, 19, 20, 36
Identity as an older adult	Positive experiences of identity while aging in place	Enjoying independence and a sense of purpose	“I’ll be doing as I please and not have to report everywhere I go, before I go, I mean, or ask.” (Porter, 1998) (p. 404) “Best part about living at home is hanging onto your independence” (Hinck, 2004) (p. 784)	1, 2, 3, 5, 9, 15, 16, 17, 23, 26, 30, 36

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[23] Participant quotations

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
		Accepting age-related challenges	"It's just down where I had a vertebra broke right in the lower part of my back. I guess at my age, it's nothing unusual." (Hinck, 2004) (p. 785)	9, 18, 23, 26, 36
		Identifying as part of a valued community	"Dignity is being recognized as a full adult who is due respect, whatever the physical condition or appearance." (Black et al., 2015) (p. 232)	6, 7, 9, 13, 22, 23, 27, 28, 29, 34, 36
	Threats to identity	Health and functional challenges	"And when I got sick, and had the stroke I couldn't put my feet like this like I used to, you ain't have the strength to stand up and it was hard. We've got pride!" (Crist et al., 2006) (p. 115)	9, 10, 17, 18, 19, 23, 24, 25, 26, 31
		Needing help from others	"And then to talk about the reality, that I may need, sooner or later, I may need help from people that aren't accepting or prepared, or even knowledgeable." (Boggs et al., 2017) (p. 1548)	2, 3, 5, 9, 10, 12, 17, 18, 19, 20, 21, 31, 34, 35
		Stopping driving	"I can't drive my car to go to physical therapy and I have to ask somebody to go anyplace and that's aggravating." (Heinz et al., 2013) (p. 47)	11, 12, 13, 17, 21, 23, 31
	Approaches to threats to identity	Taking control of care/negotiating relationships with caregivers	[importance of being able] "to supervise the boy who does the yard work." (Krothe, 1997) (p. 219)	2, 5, 10, 15, 17, 20, 35
		Focusing on strengths and preserved abilities	"I do not want to focus on [Alzheimer's]. I do not need to. So far, we are going along fine." (Beard et al., 2012) (p. 4)	1, 2, 5, 6, 7, 8, 9, 10, 15, 17, 18, 19, 23, 25, 26, 30, 31, 36
		Adapting tasks and routines to new limitations	"I've worked it out. I really don't stand up and walk up the steps. I kind of crawl up. I put my hands on a couple of steps up. I don't touch my knees. I put my feet down. You can learn how to do something if you have to." (Hinck, 2004) (p. 787)	1, 6, 8, 9, 15, 18, 19, 23, 25, 26, 30
		Drawing on personal and cultural philosophies of aging	"We Chinese are like this. You don't need ... 10 abalones....You cannot eat them all." (Li et al., 2017) (p. 4)	2, 9, 16, 23, 27, 30, 31, 34, 36
	Consequences of	Uncertain and disrupted identity	"I feel like a useless slug. Sit upstairs, sit on my ass, watch	11, 13, 22, 31, 33

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
	unmitigated threats to identity		TV...bitch about my aches and pains, and...the doctor has me taking so many pills, I'm surprised I don't light up at night." (Kohon and Carder, 2014) (p. 50)	
		Avoiding care	"I am completely alone; I have no one to help with home care, and I would much rather die than be dependent on another individual." (King and Dabelko-Schoeny, 2009) (p. 19)	5, 9, 12, 18, 31, 34
		Receiving poor quality care	"So there wasn't a lot of eye contact. It didn't feel like much of a caring connection. And it is only later, as I reflect back, you know, she may have been uncomfortable with our relationship." (Butler, 2017) (p. 390)	2, 5, 10, 12, 20, 31, 34, 35
Connectedness	Positive experiences of connectedness while aging in place	Feeling like part of a strong, intergenerational community	"The ones who are seniors now, are the ones who paved the way for younger folks to be able to be out, to at least have some of the safeguards and security to be more open about sexual orientation." (Boggs et al., 2017) (p. 1550)	6, 7, 9, 13, 14, 15, 22, 23, 27, 28, 29, 30, 34, 37
		Appreciating longer-distance connections (technology, people-watching)	"I sit in this chair most of the time. I can see everything from here." (Rosel, 2003) (p. 83)	2, 4, 6, 7, 9, 14, 16, 21
		Experiencing connection through religion	"It's really nice to have a bunch of older friends like that because your kids grow up and go in different directions. At least with these gals, we've got things that we do together. We get to visit with different people from church over coffee or lunch, which is nice." (Yamasaki, 2015) (p. 70)	7, 24, 27
		Volunteering and reciprocity	"I wouldn't know what to do myself if I weren't involved with helping people." (Rosel, 2003) (p. 87)	6, 7, 8, 9, 13, 15, 22, 23, 24, 27, 29, 37
	Threats to connectedness	Trauma and discrimination	"I observe women who suffer abuse—black eyes. I hear a lot of verbal abuse." (Bowland, 2015) (p. 176)	12, 13, 22, 23, 24, 28, 34, 35, 36
		Technology	"I am upset with people that are using it [computer] as a social	14, 16, 21, 23

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
			contact. I mean it seems to me to be kind of counterproductive.” (Heinz et al., 2013) (p. 47)	
		Health and sensory issues	“When I was diagnosed with Alzheimer’s . . . I told everybody . . . so everybody knows I have it. If I had to do it over again, I’d tell . . . just a few of my close friends. Because people look at you differently . . . you just aren’t looked on as capable anymore . . .” (Black et al., 2015) (p. 235)	8, 12, 18, 22, 23, 27, 28, 31, 36
		Family dynamics	“I may be ready to go to bed by the time it's possible to reach our son. And if we want to reach him, we don't want to bother him at work.” (Birnholtz and Jones-Rounds, 2010) (p. 148)	1, 2, 3, 11, 12, 14, 19, 20, 21, 34
		Neighborhood demographics and infrastructure	“During the day time there is nobody there except for two houses—where I live and [one other]. So that is probably one of the most lonesome areas; when you know there are those houses and there’s nobody in them during the day because all the families are gone.” (Cook et al., 2007) (p. 207)	11, 12, 13, 20, 21, 23, 29, 32, 33, 37
	Approaches to threats to connectedness	Community organizing and infrastructure building	“A lot of the reasons [for the neighborhood collective] were people recognizing that we are going to need to age in place, and we are not going to be able to drive around, and we want to know our neighbours, and we want to create friendships, and all of that. And this was a way to build social capital in just this little part of the neighbourhood.” (Dobner et al., 2016) (p. 205)	13, 22, 23, 27, 28, 29, 37
		Setting boundaries and avoiding social time when needed	“I treasure my naps. I take a nap every day and I will turn the ringer off on the phone. (Birnholtz and Jones-Rounds, 2010) (p. 149)	2, 3, 14, 24, 34
		Making use of technology	“I actually hoped that this kind of device would be created and I want one. As I age and become lonely, it is necessary to have this kind of device to go through daily lives”. (Steggell et al., 2010) (p. 443)	14, 16, 21

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
	Consequences of unmitigated threats to connectedness	Isolation/lack of social stimulation (unmet social needs)	“I have no friends here and no one to help.” (Bowland, 2015) (p. 176)	5, 11, 12, 13, 17, 19, 20, 21, 22, 23, 24, 36, 37
Place	Positive experiences of place while aging in place	Home as personal	“This house is full of me.” (Rosel, 2003) (p. 80)	4, 5, 6, 7, 8, 9, 13, 19, 25, 31
		Home as private	“We don’t want to leave it because this is where we live, and we like our privacy and I like having the yard to work in. So I don’t know how we’ll ever leave this place.” (Lien et al., 2015) (p. 11964)	2, 4, 8, 9, 14, 16, 20, 25, 34
		Familiar, accessible neighborhood	“’Course we lived here so long that I know what we grew in this field and that field. And it just does me good to just get out.” (Hinck, 2004) (p. 784)	4, 6, 7, 9, 11, 13, 14, 15, 25, 27, 29, 30
	Threats to sense of place	Issues with home upkeep	“There’s more upkeep as your home gets older.” (Cook et al., 2007) (p. 209)	1, 2, 4, 8, 9, 11, 15, 21, 23, 25, 26, 31
		Home care workers entering private home space	“I think one issue would be if you thought that somebody was coming who was not in the gay community, you’re going to have to de-gay your house.” (Bradford et al., 2016) (p. 113)	2, 5, 9, 10, 12, 20, 28, 34, 35
		Discrimination, violence, and trauma	“I didn’t know that men harassed women and people broke into each other’s apartments until I came here.” (Bowland, 2015) (p. 176) “I want to move away from . . . due to guns and knife fights.” (Bowland, 2015) (p. 176)	12, 13, 20, 22, 23, 24, 33, 34, 35, 36
		Financial concerns	“I simply need to have health coverage so I do not lose my homestead should anything happen to me.” (King and Dabelko-Schoeny, 2009) (p. 18)	8, 12, 19, 22, 23, 31, 32, 35
		Problems with neighborhood environment	“This area has almost been given to the university for student rental. I often think that I’m a thorn in	11, 12, 13, 17, 20, 21, 23, 29, 33, 34

Third-order construct	Second-order constructs		First-order constructs[23]	Source study numbers
			somebody's side because I live here." (Powell, 2016) (p. 546)	
	Approaches to threats to sense of place	Making adaptations to home and routines	"The showerhead in the master bathroom was too difficult for me to adjust, so we put in the removable showerhead on a bar where the height can be adjusted. We also remodeled the kitchen." (Lien et al., 2015) (p. 11966)	1, 2, 6, 8, 9, 11, 15, 18, 19, 23, 25, 26, 28, 30, 35
		Community organizing and village building	"We have to roll up our sleeves and figure out how we are going to get our needs met." (Dobner et al., 2016) (p. 204)	13, 22, 27, 28, 29, 37
	Consequences of unmitigated threats to sense of place	Feeling out of place	"The house is mine, I bought it, but sense of belonging, well, not much" (Li et al., 2017) (p. 4)	11, 12, 13, 20, 22, 33, 36
		Experiencing place as unsafe or no longer private	"When I get home, I stay home, I don't want to run into any of these people, I don't want to be trapped on the elevator with anyone . . .you wouldn't want anybody to know that you were gay in this building. You would be in trouble; there would be consequences." (Boggs et al., 2017) (p. 1549)	13, 16, 20, 22, 24, 33, 34
		Feeling trapped	"It's like residents are being warehoused here." (Bowland, 2015) (p. 176)	13, 22, 23, 24, 31

Discussion

Summary of Findings

The purpose of this systematic review and meta-ethnography was to synthesize qualitative research on experiences of aging in place in the US. Our primary finding relates to the dynamic nature of aging in place, driven by the tension between threats and agency across the three core experiences of identity, connectedness, and place, as well as the balance of resources and restrictions that determine an individual’s sense of agency (Figure 2). In contrast to widely used definitions of aging in place that imply passively remaining in a positive and familiar setting, we found that people aging in place engaged in significant work to cope with unpredictable needs and challenges by changing their mindset, adapting their home environment to accommodate new needs, and finding different ways to connect with important people in their lives. Where threats to aging in place outweighed an individual’s sense of agency, the consequences included feelings of uncertainty, isolation, and dislocation.

Our meta-synthesis resulted in a model of aging in place as a dynamic process of balancing threats and agency in the context of experiences of identity, connectedness, and place. Two existing conceptual models focus specifically on aging in place: Cutchin’s theory of mediated aging-in-place (Cutchin, 2003), and Ahn, Kang, and Kwon’s model of aging in place as intention (Ahn et al., 2019). Neither of these models was developed through a systematic review process: Cutchin drew on the results of a qualitative study, and Ahn and colleagues describe a review of theoretical and empirical literature which does not seem to have involved a systematic process, generating hypotheses that they tested through a quantitative survey. Each of these models involves features of our Dynamic Tension Model of Aging in Place, including instability and an understanding of experiences as informed by sense of person, place, and connection. However, their narrow *a priori* attention to service provision and intention respectively does not allow for theorization on how different experiences of aging in place are shaped and how they relate to each other. As a result, these models of aging in place are limited in their scope and applicability. In contrast, our Dynamic Tension Model of Aging in Place was informed by a systematic review of qualitative studies, contributing a comprehensive, integrated model that incorporates both the nature of the core experiences of aging in place and the processes that shape them and hold them in tension.

Our holistic model addresses a gap in the existing systematic review literature in this field. The two previous systematic reviews specifically about aging in place focus on technologies, without considering how these relate to other experiences of aging in place. Peek et al. (2014) grouped qualitative, quantitative, and mixed-methods studies into descriptive themes, including concerns, benefits, needs, and alternatives in relation to technology. In their conceptual model these themes were all connected to the outcome of pre-implementation acceptance, but the authors did not model the interactions between them. This review also included a study conducted in continuing-care housing, since here aging in place was seen as an attribute of the types of technologies considered rather than being associated with a particular living setting. Graybill et al. (2014) review of cost-effectiveness of aging in place technologies, defined as home and environment modifications and telemedicine, included only economic evaluation studies, meaning that their findings do not contribute a conceptual understanding of experiences of aging in place. However, they drew useful conclusions on the need for higher-quality research as well as a more comprehensive approach to outcomes including quality of life for people aging in place. The scope of our systematic review, integrating evidence from a wide spectrum of experiences, provides a comprehensive and holistic model of aging in place.

Although the US older adult population is becoming more diverse, the included studies in this meta-ethnography were limited in their representation of geographic and racial/ethnic diversity. This is a concern in the context of the rapidly growing literature on the impact of life-course racism on health and aging (Gee et al., 2019), and it reflects the underrepresentation of communities of color in research in general. It is crucial to include diverse older adults in the literature on aging in place and to ensure that their unique experiences and needs are represented. “Aging out of place” has become an increasingly important concept in gerontological literature over the past decade, referring to experiences of aging for immigrant elders (Vespa et al., 2018). Although the concept of aging out of place appears to include institutional settings as well as aging in place, there is shared ground with the Dynamic Tension Model of Aging in Place we present here; a concept analysis of aging out of place for newly arrived immigrants identified loneliness, boredom, and family conflict as the primary consequences for older adults, as well as role loss and nostalgia (Sadarangani and Jun, 2015). More research with diverse populations is needed to explore how specific experiences including immigration, discrimination, and culture intersect with underlying common processes involved in aging in place.

Strengths and Limitations

A key strength of this systematic review is the breadth of its scope; to the best of our knowledge, this is the first review to systematically examine the holistic experience of aging in place rather than focusing on an isolated aspect such as technology. This was facilitated by our use of broad search strategies for six bibliographic databases, carefully designed with a specialist librarian to increase sensitivity. Our specific focus on aging in place in the US also constitutes a strength, since our findings are situated in a common context that facilitates comparison and translation of constructs across studies. In addition, we aimed to maximize the validity of this review through careful attention to our professional and personal experiences relating to aging in place, exploring together how these might affect our conceptual thinking and reflexively interrogating our emerging model against our prior assumptions.

Despite the strengths of this systematic review, several limitations must be acknowledged. First, we confined our search to peer-reviewed studies published in English before May 2018. Therefore, our findings might not be generalizable to non-English speakers. Second, grey literature was not searched in this systematic review, meaning that there may be additional sources of relevant data that were not included here. Third, qualitative synthesis is a creative, interpretive process, and given that definitions of aging in place vary, another team might have selected different articles and generated different meta-ethnographic findings. To address potential sources of bias, we designed this review following best practice protocols and using multiple strategies to increase rigor and reproducibility.

Conclusions

This systematic review and meta-ethnography contributes a novel conceptual model of aging in place in the US, highlighting dynamic processes shaped by the tension between agency and threats to identity, connectedness, and place. Our findings suggest directions for future research, including exploring aging in place in diverse populations and evaluating how the provision of services could bolster agency and help people aging in place to counterbalance threats to their preferred experiences. Drawing on this conceptual model may help nurses and other health professionals to understand individual trajectories of people aging in place and provide person-centered support.

Addendum

We conducted the original literature search for this systematic review in May 2018. In November 2019, after the manuscript was accepted for publication, we repeated the literature search to identify relevant literature published since May 2018. We located one new study that met all of our eligibility criteria (Strommen and Sanders, 2018). Given the growing importance of aging in place in the US, we intend to update this systematic review and meta-ethnography in the next five years.

Declaration

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Chapter 3 : “You’re stuck. And you’re stuck with the people that help you.” A qualitative study of the experiences of homebound people

Background

For older adults in the United States (US) today, the concept of aging in place–continuing to live in one’s current home for as long as possible–is important in shaping both cultural norms and policy provisions. As the US older adult population grows, aging in place is often portrayed as a more appealing alternative to institutional care that puts less financial pressure on federal and state funds and preserves independence and comfort (Bipartisan Policy Center, 2016; Vasunilashorn et al., 2012; Vespa et al., 2020). However, aging in place can also be a restrictive experience, particularly for older people who are “stuck in place” with no option to move elsewhere (Erickson, Call, & Brown, 2012; Torres-Gil & Hofland, 2012) and for those who are homebound. The most recent national estimates available indicate that around 1.6 million older adults in the US were homebound in 2019, more than the total nursing home population (Ankuda et al., 2021; Ornstein et al., 2015). Risk factors associated with being homebound include older age, female gender, being a person of color, having a low income, living with multiple chronic health problems, and having a lower level of education (Ko & Noh, 2021; Lee et al., 2022; Ornstein et al., 2015). Older people who are homebound have higher rates of depression compared to those who are not homebound (Xiang & Brooks, 2017). More than one in three homebound older adults are socially isolated, compared to 25% of the general older adult population, and social isolation is also a risk factor for becoming homebound (Cudjoe et al., 2022). Being homebound is associated with increased mortality, particularly in combination with social isolation, and those in the last year of their lives are more likely to be homebound (Sakurai et al., 2019; Soones et al., 2017). Homebound status is also linked to household and environmental factors such as living alone and poor home entrance/exit accessibility (Lee et al., 2022).

Epidemiological findings on experiences and outcomes for homebound people based on national survey data are complicated by issues with defining what homebound means, as well as challenges with including those who may be less likely to participate in research studies. Some studies use established criteria such as Medicare or Veterans Affairs home health eligibility to select their samples; others draw from populations already receiving home- and community-based services, relying on these services' eligibility criteria as a proxy (Qiu et al., 2010). Since around 40% of homebound people receive home health care services each year, and only 11% have access to home-based primary care, such samples only capture a fraction of the homebound community. Still others adapt or develop their own survey questions to assess frequency and difficulty of leaving the home and may distinguish between completely and semi-/mostly homebound participants (Ornstein et al., 2015). In reviews of the literature, Lee et al. (2022) and Ko et al. (2021) noted that frequency of leaving the house was the most commonly used method of assessing homebound status, with other studies using functional difficulty or a combination of the two. Going out once a week or less is often but not universally used as the threshold for being homebound. Prevalence estimates for being homebound range from 3.5% to 39.8% depending on the population and measures used (Lee et al., 2022). It is likely that the experiences of homebound people vary widely even within frequency- or disability-based categories, due to factors such as access to care and support, financial security, environmental accessibility, and previous life challenges. The daily life of someone who never leaves the house but lives with close family members and receives frequent visits from friends and service providers is very different from a socially isolated, lonely homebound person struggling to find help with daily tasks.

Few previous studies have used qualitative research methods to explore experiences of being homebound in the US. Several studies sampled from a homebound population not because they were focused on the experiences of homebound people but due to factors associated with being homebound, such as having high mortality rates (Carrese et al., 2002) and using mobility devices (Porter et al., 2011); the findings of these studies do not address the specific experience of being homebound. Others have investigated the healthcare experiences of the small subset of homebound people receiving home-based primary care (LaFave et al., 2021; Mickler et al., 2021; Shafir et al., 2016). Even for those with access to these services, contact with healthcare providers represents only a small part of their day-to-day lives. A pilot study with eight participants explored loneliness and social isolation among people receiving home-based primary care in the Midwest, identifying barriers to social participation including disabilities and health problems, mobility issues, and the lack of accessible transportation (Bedard-Thomas et al., 2019). The authors also emphasized that most of the socially isolated homebound people they interviewed did not report subjective feelings of loneliness. Huang et al. (2016) focused on attitudes to telemedicine and technology among homebound people receiving home care; participants had mixed feelings, due to barriers to technology use and concerns about missing in-person visits. One more recent research study did aim to explore the day-to-day experiences of homebound people in depth, publishing two papers drawing on the same sample: one focusing on social and lived experiences (Cheng et al., 2022) and the other on healthcare (Cheng et al., 2020). In terms of social and emotional experiences, Cheng and colleagues described the physical and mental health issues that restricted older people to their homes, as well as activities they missed and their feelings about having to depend on others. Findings from the healthcare experiences paper focused on challenges with access to and quality of care. This study was conducted on the East coast in a small city and its surrounding rural communities. More qualitative research on the experiences of homebound people in other settings is needed to expand our understanding of this phenomenon, especially for the majority of homebound people who do not receive home-based primary care services.

Homebound people experience high rates of health and functional challenges and have poor access to healthcare, and homebound status disproportionately affects those who are already marginalized due to racism, ageism, and poverty. However, little is known about their day-to-day experiences due to the lack of qualitative research in this area. The aim of this grounded theory study was to explore the experiences of homebound adults living in the San Francisco Bay Area and to build a conceptual understanding of what it means to be homebound.

Methods

This study was designed following the principles of grounded theory (Charmaz, 2014) and received approval from the University of California San Francisco Institutional Review Board (#18-25363). Homebound people of any age living in the Bay Area were eligible to participate. For several reasons, self-definition as homebound was used instead of existing criteria such as Medicare or Veterans Affairs eligibility. First, I hoped to reach a wider group beyond the minority of homebound people who receive formal home- and community-based services. Second, I aimed to learn from homebound people about how they define themselves. This meant, for example, that I would include people living in institutional/communal settings if they self-defined as homebound. Flyers and recruitment emails were distributed through community programs and clinical services targeting homebound people, including meal delivery services, home library services, outreach/befriending, and home-based primary care. For interested participants, I used an initial telephone screening protocol to informally assess cognitive and linguistic ability to complete the interview in English, as well as ensuring participants understood the goals and procedures of the study. I also used a brief, optional demographic form to collect information on age, gender, race, ethnicity, living situation, and socioeconomic status. Participants received a $30 Visa gift card for each interview completed.

I began this study in late 2018, and the first seven interviews were conducted in person, in participants' homes. Seeing people within their living context was an important part of the study; I wrote memos on the characteristics of their homes and neighborhoods, and many participants showed me around their homes during the interview. However, the COVID-19 pandemic made home visits impossible from early 2020 onwards. I completed the remaining interviews by Zoom or telephone. I attempted to contact the initial seven interviewees again for follow-up interviews. Two completed a second interview, one had died, and the others did not respond to my messages.

I created the interview guide through an iterative process, refining it as I conducted each interview and through discussion with fellow doctoral students. Questions focused on how and when people became homebound, their day-to-day experiences, and access to community and support (see Supplement for sample questions). For the interviews conducted in 2020 and later, I added questions on the impact of COVID-19. Interviews were audio recorded and transcribed verbatim, some by me and some through an online transcription service.

Grounded theory analysis was conducted concurrently with data collection. I group coded sections of the first three transcripts with peers from my qualitative research group, initially conducting open coding by hand with printed transcripts. Names and other identifying details were removed from transcripts, and they were uploaded to ATLAS.ti coding software (*ATLAS.Ti 22 Mac*, 2022). Analysis was inductive; I did not create an *a priori* codebook but developed codes through open coding, memoing, and iterative edits to the codes and their definitions. After the initial group coding, I completed the rest of the coding and analysis process independently. I developed the results presented here through cycles of focused coding and theoretical coding. Pseudonyms are used throughout to protect participants' identities.

Results

Sample characteristics

Table 3.1 Sample demographics

		N=15[1] n (%)
Age	*Range*	65-96
	Mean (sd)	81 (9)
Gender	*Female*	7 (47%)
	Male	8 (53%)
Race	*Black*	1 (6%)
	White	14 (93%
Living alone		13 (87%)
Housing	*Rent*	8 (53%)
	Own	6 (40%)
	Nursing home	1 (6%)
Education	*Graduate school*	3 (20%)
	College degree	7 (47%)
	Some college	2 (13%)
	High school	3 (20%)
How long homebound	*1-3 years*	11 (73%)
	4-6 years	2 (13%)
	7-9 years	2 (13%)
Paid caregiving[2]	*None*	5 (33%)
	Once a week	1 (7%)
	Twice a week	6 (40%)
	4+ times a week	2 (13%)
	Nursing home	1 (7%)

[1] Percentages may not add up to 100% due to rounding

[2] Pre-pandemic figures. Note that one participant, interviewed twice, was receiving paid care 4+ times a week in 2018 but reduced this to none after the start of the pandemic

Of the 15 participants, seven were female and eight were male. Ages ranged from 65 to 96, with a mean age of 81 years. Fourteen participants were White, and one was Black. One participant lived with her husband, one shared a room in an institutional setting (nursing home), and the rest lived alone. Of the 13 participants living alone, five had family nearby and received support from them at least once a week. Most of the others had friends, neighbors, or volunteers they could ask for help with errands but didn’t receive significant help at home from these people. One third of participants received no paid caregiving, whereas more than half of the sample had help for a few hours from a paid caregiver at least twice a week. Payers included Medi-Cal, long-term care insurance, Support at Home vouchers, and self-funding.

Eight participants were renting their homes, six were homeowners, and one was living in a nursing home. Three participants reported no major health issues; all of the others reported multiple health problems, including heart failure, cancer, stroke, falls, diabetes, and depression. Two participants were interviewed twice, first in 2019 and again in 2021, giving a total of 17 interviews. Interview length ranged from 32 to 175 minutes, and the Zoom/phone interviews were generally shorter than those conducted in person, with participants becoming tired more quickly. Total interview time was approximately 22 hours. Table 3.1 summarizes the demographic characteristics of the sample.

Qualitative results

The results presented here center around two interacting aspects of homebound people’s experiences – being stuck, and still being able to make choices for oneself. The tension between autonomy and dependency was at the heart of the experience of being homebound. There were two main ways in which participants felt stuck, beyond their physical confinement. They were stuck with the inadequate help they received, and they felt stuck with the few options that were available to them in their lives. In terms of retaining or rediscovering autonomy, they demonstrated ways in which they continued to have control over aspects of their daily lives, and they emphasized the attitude they chose to take in relation to their situation.

Homebound as stuck: "It's all limited, everything is limited"

Among the homebound people interviewed for this study, their primary experience was of being stuck – stuck in one place, stuck with inadequate help, and stuck with few options. Dependence on care arrangements and lack of choice in daily life was generally more salient than the physical confinement to one place, and financial limitations compounded this, limiting options for support and transportation. Jason, 71, was living in a shared room in a nursing home after a stroke; he felt he was in a "holding pattern." Rosa, 92, rarely left her rent-controlled apartment after breaking several bones in a fall. She said, of her life as a homebound person: "It's all limited, everything is limited." Others emphasized their sense of isolation and of their world narrowing. Participants identified physical health issues as the primary driver of their homebound situation, including heart disease, vertigo, falls, digestive problems, pain, and fatigue. These conditions made it harder for them to be out in the world, even when they did have assistance available. For some, concerns about neighborhood safety exacerbated this; Rachel said, "It's just unfortunately a very scary neighborhood. So you have to live inside, you cannot live outside," and Joyce: "In this building I'm safe. Out of this building, I'm not." Both were living in the Tenderloin in San Francisco.

Stuck with(out) care

Although participants understood being homebound in terms of physical confinement, most felt that their daily experiences of being homebound were dominated by feelings of dependence on others. As Rosa said, “You’re stuck, you’re stuck. And you’re stuck with people that help you.” Her mobility had been greatly affected by a fall three years prior, and she was frustrated both by needing help at home and not being able to find or keep a good caregiver. Being stuck in terms of relying on caregivers took many different forms. Some needed services that would not visit them at home or that they could not afford. Such unmet needs included personal care, handyperson, hairdresser, cleaning, exercise instruction, podiatry, dentistry, and support with bureaucracy and technology.

Those who did have caregivers still often had difficulty getting their needs met. Rosa had tried eight or nine different caregivers; she reported issues such disengagement and indifference, lack of basic cooking, housekeeping, and personal care skills, or unwillingness to help with daily tasks. In some cases, agencies placed restrictions on the tasks caregivers were permitted to do. For example, “light housework” excluded cleaning tasks that participants could not do alone but felt were regularly necessary. High staff turnover also made receiving care feel unstable and inconsistent.

Not having enough help meant that even those who were sometimes physically able to go out were effectively stuck at home. Reductions in caregiving hours due to budget cuts and pandemic-related restrictions left homebound people struggling without essential services: “They [older people] are being told that it might be easier if you just disappear. I don't feel that there's a support system. There is not a support system that's available" (Rachel). Marie, 70, owned her apartment, but it was cluttered and in poor repair, and her low monthly income barely covered her essential costs. She described a sense of injustice at being stuck without care, imagining she would feel more free if she had access to more support:

> But usually most people who are homebound have people caring for them. Or they have people. I mean, I see people walking them to the store. Walking them to the streets, or driving them places. But I don't qualify for any of that. And the one I can get, which is still a stretch, is only give me a little bit.

Dependence on caregivers also shaped daily routines, as homebound people organized their lives around care availability:

> I'm very confined by the hours […] You know I get up early, you know lunch is delivered by [service], my helper leaves, I take a rest, my physical therapist comes – so I never used to be this structured. I mean I used to be much more free flowing, I used to be much more of a free spirit. (Rachel)

Although some participants in this study were able to manage more easily than others and had fewer unmet needs, most felt confined by depending on or waiting for help.

Stuck with few options

Not having a choice was at the core of the experience of being homebound, as described by the homebound people in this study. Almost all participants felt they were disempowered and stuck with a limited set of options: "I am homebound. I cannot go out, I cannot go swim, I cannot teach, go here, go there. I am stuck" (Rosa, 92). Joyce, 83, was living in subsidized senior housing in the Tenderloin. She had had to sell her house and spend all her retirement savings on medical bills for her husband, who had died of cancer. She summarized her pragmatic, if resigned, reaction to this experience: “What choice do you have? When you have no choices, you do what you have to do. When you have options, you use the best option for you. That’s it.” She would have liked to have moved to a different neighborhood but was pessimistic about her chances of making a successful application: “They have 200 people on a list, you’re gonna be at the bottom of that 200.”

At times, thinking about alternative living situations could help with acceptance – whether hospitalization, being stuck in a nursing home, or even imprisonment. For Jason, a homebound nursing home resident living in a shared room, home was associated with choice: **“**Home would be some place where I could close the door, turn the lights on or off at my choosing, close the door, have silence when I want, um, not have to hear some other conversations going on or whatnot.” Listening back to our interview recording, I often struggled to hear his words over the background noise – his roommate’s television, music from the group activity happening in the day room, the nurses’ conversations in the hallway. Jason’s experiences chimed with the fears of those who were homebound at home but imagined nursing homes as a worse option, with even fewer choices available:

> But I mean, actually, I'm glad that I'm not in a home where I'm stuck. My aunt's in a home, but she's in a real nice home in Vegas, and her daughter's paying for her. But still she's stuck there right now with the COVID. (Marie, 70)

For some, their emotional connections to their physical space and treasured objects within it tempered their frustrations with being stuck at home. Similarly, those with experience of homelessness, trauma, and serious health problems earlier in life generally found it easier to cope, reminding themselves that things could be worse.

Choosing to make your own decisions: "I continue to choose to live here"

Although they frequently expressed feelings of powerlessness and lack of options, participants also emphasized the choices they *were* able to make, in relation to both their circumstances and their outlook. The interview guide did not initially include questions explicitly about autonomy, but most participants spontaneously emphasized this aspect of their lives. The choices they made ranged from continuing to live in conditions they recognized as unsatisfactory, not using prescribed mobility devices or medications, and staying at home all the time. Some highlighted ways in which they leveraged their own power with others, including engaging in conflicts with nursing home staff and choosing not to let anyone into their apartment. Such expressions of personal agency served to differentiate participants from the other homebound people they saw as more powerless, as well as separating themselves from aspects of their own situations that they viewed as weak, limiting, and disempowered.

When asked for his definition of homebound, David, 65, immediately distanced himself from his negative image of a homebound person:

> Well, what I think of is a person who can never leave their home, period, that is restricted, that doesn't have enough resources internally to function in a way that allows them to have free choice to leave. No, being in the world is much more difficult for me, I can walk out the front door, though I can only go about 15 steps at a time, so I have to stop every 15 steps. You might already sense I'm a very willful person, and my will keeps me going. And, er, you know they've offered me an electric wheelchair but I want to take 15 steps rather than sit in a chair. So I will do that, as long as I can.

He asserted his own agency by continuing to go out alone and by refusing to use a wheelchair, even if that might have made his life easier; he struggled with the debilitating health effects of several terminal conditions and had fallen multiple times. He also emphasized that he was choosing to continue to live in his current setting, a Single Room Occupancy (SRO) hotel, which seemed unsatisfactory to him and where he had witnessed multiple traumatic and violent events: “I’ve seen things and been exposed to things that I never would imagine I would have encountered in my life. But yet I continue to choose to live here.” However, he did acknowledge that the illness he had experienced for years before becoming homebound, as well as its impact on his personal life, felt like an imposition – a denial of the natural order of things: “Things were imposed upon me that I wouldn’t have chosen, and there wasn’t the natural progression of growing older.” His “willful” decisions appeared to help him assert power over a life in which many things had been out of his control.

Elizabeth presented her situation very differently, emphasizing the ease and comfort she felt. At 96, she was the oldest participant, lived in a large house that she owned, had no financial concerns, and was happy with her care arrangements. As such, her situation did not feel as restrictive to her as was the case for others – it represented more of a “natural progression” rather than an imposition, after a life she felt had been long and full. Still, she too was careful to underline that she saw herself differently from other homebound people – for her it was a choice, not an imposition: “I’m not really homebound, it’s really by my choice that I’m not going out as much as I used to.” “It’s laziness in some way, you know. Yeah, I think it is. I’m so comfortable doing what I’m doing, I don’t need to, you know.”

For her, having to have live-in care would represent the “stuck” feeling that other participants seemed to associate with being homebound:

> Well I like my privacy, and I wouldn’t want to have to eat with somebody every night, and be – have somebody around the house all the time, and never leave, you know, I don’t know – to me that would be uncomfortable, I may be stuck with it, I may not have a choice, I am resigned to the fact.

By contrast, Clara also felt that many aspects of her daily life were out of her control, but opportunities for her to assert agency also felt overwhelming to her. She lived close to family in a house they owned, but she was troubled by rumination about whether to move to an assisted living or nursing home setting or stay at home:

> Who knows, maybe there is life after, but still I am telling myself, it’s just this one which I know, and for now we know, because nobody… so we have to, I have to, I have to enjoy every moment what I have, but then I just… What shall I do now, how shall I do, how shall I arrange?
>
> Will I change my thinking? Because I am at the point, probably I cannot change my life. And the big question is, is it better to stay here or to start to move?

She understood her situation as falling somewhere between choice and imposition and had difficulty making sense of it. The experience of witnessing her mother’s prolonged and painful death from dementia in a nursing home colored her thinking about aging and was physically present throughout her home; she showed me photos, letters in which the handwriting traced a progressive decline, and even a room she had preserved in her mother’s memory.

Clara also struggled with smaller, daily decisions, concerned that she could be making different choices to improve her day-to-day life but felt unable to do so. For example, she expressed significant sadness and frustration over the condition her dining room, where the table was covered with paperwork and medication boxes. It represented the ways in which her life had changed – she no longer ate at the table or had guests over. She berated herself for not choosing to clean and organize instead of watching television that she did not particularly enjoy.

The tension between autonomy and powerlessness was central to the lives of the homebound people I interviewed and to their sense of self. While they varied in their access to resources that could expand the range of options available to them, almost all were careful to emphasize their retained autonomy, even while describing the many frustrations and restrictions they experienced.

Choosing your approach to life: "It's the attitude you have to have. That's what counts"

Many participants described their approach to life as a combination of remaining positive and hopeful, being determined, and focusing on the present moment. They often drew comparisons between their health and living situation, which felt permanent and beyond their control, and their perception that they were in command of their attitude and orientation towards life. As Rosa noted, "I am stuck. But it's the attitude, you know, you have to have. That's what counts." At times, this was clearly framed as a personal responsibility: "So, you know, you can fall into your own trough if you're not careful. You know, you have to work on it. You have to work on it" (Elizabeth).

Participants frequently drew comparisons between their present situations and challenges they had experienced in the past or could imagine facing. These served both to illustrate their determination and survival instinct and as a reminder of how difficult their current circumstances were too. Several participants referred to imprisonment as a parallel for their situation: "I mean I've often wondered how prisoners cope with their confinement. I mean I try to, you know my psychologist told me is to try to distract yourself" (Rachel); "I've read that even people who go to prison, at first it feels horrible and then when they're released, some of them actually want to go back" (John, 89).

Others referred to trauma from earlier in their lives, including homelessness, addiction, and persecution:

> I never thought this would happen to me. I went through all the years with Hitler. Then the Holocaust. And and and and and (Rosa)
>
> By the way, this is why I'm able to actually deal with this isolation. Because to be quite frank with you, I've isolated almost all my life. Because in order to survive severe, tremendously severe homelessness, chronic homelessness, in order to survive that, you have to be by yourself (Larry, 83)

Comparing themselves to other older people in worse circumstances, such as in poor quality housing or nursing homes, helped some to accept the challenges of their lives and to sustain their positive attitude:

> I have to take into account, let's say there's a downtown SRO, single-room occupancy for many brother and sister citizens, and let's say a fellow is on the 10th floor of a 13-floor tenderloin and the elevator has stopped functioning. He's in a lot worse shape than I was. (Michael, 81)

Similarly, the positive attitude proposed by so many as the ideal was easier to achieve for those who felt they had already lived a full life. These participants were generally older and living in relatively comfortable residential and financial circumstances, with a sense of contentment and spiritual ease:

> When you reach my age, I've seen it and I've done it, whatever it is that I wanted to do in my life, I feel that that has been accomplished and I'm ready to, whenever, I'm ready to [die]. (John, 89)

Several participants did acknowledge that they found it challenging to maintain a positive outlook, even though they felt confident that it would be beneficial to do so.

Brian, 82, who lived in a house he owned and was homebound due to a combination of health problems (heart disease and diabetes) and sheltering in place during the pandemic, experienced a more acute sense of loss: “It’s a year out of my life at a time when years count.” Marie felt strongly that her isolation, lack of help, and multiple physical and mental health problems left her with little ability to be present and take care of herself:

> I'm just trying to live in the now, right now. But I mean, I'm doing the best I can, but it's like even just small things are hard to do. I'm supposed to floss my teeth twice a day, brush my teeth, wash my face. And now I'm having some problems with my hair falling out. And I'm supposed to do exercise, which I haven't done.
>
> And sometimes I just say, "What's the use?" I'm by myself. I don't have friends. I don't have partners.

Similar to their narratives of autonomy and control, the homebound people in this study demonstrated their resilience and determination as they described their approach to life and its challenges. Those who found such an orientation to be out of reach, due to the mounting difficulties they faced each day, interpreted this as a personal failing that exacerbated their sense of powerlessness.

Discussion

For the older people who participated in this study, being homebound meant being stuck – stuck in place, stuck with inadequate help, and stuck with few options. Their daily lives and routines were deeply impacted by their dependence on the limited selection of people and services that would come to their homes to help them. Although some expressed regret about no longer being able to participate in activities outside the home and longed for support to get out more often, most focused on their experiences at home and their restricted choices and unmet needs there. They simultaneously highlighted the challenges of their situations while also emphasizing the ways in which they preserved their sense of independence and autonomy. The tension between dependence, powerlessness, and autonomy was constantly present in their lives.

Several reviews have noted the distinction between two major definitions of homebound in the literature – Ko and colleagues (2021) summarize these as “confined to home” and “infrequently going outside the house.” My study findings support a focus on the experience of confinement and are aligned with the gerontological conceptual framework used by Ornstein et al. (2015), who described the “confluence of personal capacity and the ability of social support to compensate for limitations in capacity” (p. 3). Similarly, Soones and colleagues (2017) conceptualize homebound status as **“**the combination of multimorbidity, functional impairment, and inadequate social support that makes it difficult for an individual to leave home and access care” (p. 3). According to these definitions, availability of help represents a modifiable risk factor for being homebound, similar to environmental factors such as having step-free access between the street and the home. The authors of a series of German reviews and concept analyses constructed a conceptual definition of homebound, including: need for assistance exiting home and with ADLs/IADLs; feeling powerless; permanence (of homeboundness); weakness; and impaired mobility (Schirghuber et al., 2022; Schirghuber & Schrems, 2018, 2021a, 2021b). My study findings shed light on the relationship between confinement, needing assistance, and feeling powerless. Dependence on others was not simply a neutral need for help but represented loss of agency, independence, and power, reflecting the psychological burden of being homebound.

For participants in this study, experiences of being stuck and limited were closely tied to dependence on caregivers. Previous qualitative studies on experiences of homebound people by Cheng et al. (2022) and Mickler et al. (2021) similarly identified helplessness and negative feelings about dependency as central themes, as well as issues with quality and turnover in home care. My findings build on this by detailing the practical and emotional experience of being dependent on care, including for those who need support but do not have access to it. Participants felt that their lives were dictated by how much assistance they had available to them and when; some noted that this enforced structure was at odds with their personality and lifelong habits.

Several previous studies with (non-homebound) older people conclude that needing and receiving care is not necessarily synonymous with feeling dependent and powerless (Gignac et al., 2000; Hammarström & Torres, 2010; Kristensson et al., 2010; Timonen & Lolich, 2020). For some, access to home help is a key driver of preserved independence, especially when the alternative is relocation to an institutional setting. Timonen and Lolich (2020) explored independence and dependency among older adults receiving help in Ireland. They found that, for many, dependency could constitute a positive, even prestigious status, signifying that they were worthy of help and possessed sufficient social capital to receive it. Being helped by a family member or by a paid caregiver who “feels like family” could also mitigate negative feelings of dependence by suggesting a more reciprocal or voluntary relationship. The negative experiences of dependence reported by most of my study participants may reflect dominant cultural ideas in the US about the value of self-reliance and individualism, as well as the specific context of being homebound. Having to rely on outside help may feel especially restrictive when one already feels limited by confinement to the home, and there is little social capital to be gained from being cared for when no-one else is there to witness it. In a qualitative study conducted in Sweden, Breitholtz and colleagues (2013) identified the ways in which receiving caregiver support challenged (non-homebound) older people's opportunities for self-determination. They found that, in some cases, older people accepted poor care that made them feel stuck because they were afraid of being abandoned with no care at all. My findings similarly suggest that having inadequate options for care exacerbates feelings of powerlessness and dependence.

Individualistic approaches to autonomy and independence are often presented as core elements of so-called "Western" approaches to society and ethics (Hanssen, 2004), including in relation to aging; Becker described "the American ethic of responsibility for maintaining health, and thus, autonomy" (Becker, 1994, p. 67). This may reflect the dominant political and social culture in the US but is by no means universal (Hanssen, 2004). Moreover, previous research paints a nuanced picture of the concept of independence for older adults, encompassing interdependence, freedom to delegate tasks and access help, and the value of being socially independent (i.e., able to connect with others and maintain relationships) (Ball et al., 2004; Hillcoat-Nallétamby, 2014; Plath, 2008). Although the concepts are often used interchangeably, distinctions between autonomy and independence may be particularly important in the context of functional limitation; where being able to physically achieve tasks independently is no longer possible, a psychological sense of autonomy can be retained through involvement in decision-making and delegation (Ball et al., 2004). The examples of independence and autonomy given by participants in this study included choosing not to let anyone into their apartment, refusing to use prescribed mobility devices, and remaining in living circumstances that others saw as unsafe or undesirable. Some also highlighted their independence of spirit to distinguish themselves from their own image of being homebound as weak and limited. At times, this led to a delicate balance between expressing how hard things were for them and emphasizing how tough they were in surviving and fighting back. Other researchers have concluded that older people minimize their health problems and functional issues in order to retain an image of independence, autonomy, and health (Anderson et al., 2022; Torres & Hammarström, 2006). In my study, most participants did not shy away from the details of their difficult lives–they saw themselves as autonomous in spite of the limitations imposed on them. Perhaps people who are homebound feel they can no longer deny their health issues or feel compelled to acknowledge them to justify their confinement, while still needing to retain a sense of independence.

Emphasizing independence and autonomy, especially in challenging circumstances, can function to integrate experiences as an older person within one's overall life narrative (Anderson et al., 2022; Becker, 1994; Fischer et al., 2008; Severinsen et al., 2016). Indeed, remaining in a living situation that is not conducive to leaving the house frequently might in itself reflect the independent spirit that some homebound older people hoped to project. Severinsen (2016) found that those remaining in difficult housing situations "proudly" explained the ways in which their homes were unsuitable; the ways in which they faced the challenges of continuing to live there demonstrated aspects of their character that were important to them and that connected them to their lifelong sense of themselves. Others stayed in such settings because their homes held great emotional and relational meaning that was more important than accessibility or convenience. Indeed, in my study, most participants had been living in their homes for many years, whether rented or owned, and had made them their own. Previous research suggests that older adults grow more attached to their homes as their health and independence decline, perhaps because they spend more time at home (Granbom et al., 2021; Severinsen et al., 2016; Wahl & Lang, 2003). Golant's theory of residential normalcy posits two important emotional constructs for older adults – residential comfort and residential mastery – representing feelings of contentment and competence (Golant, 2012). Comfort is often associated with remaining in a familiar, homely environment, but aging in place can threaten residential mastery if older people can no longer manage personal and home maintenance tasks. Golant has since proposed the idea of "aging in the right place," emphasizing that simply aging in place, regardless of the nature of that place, is not necessarily a universally positive experience (Golant, 2015). When moving elsewhere is not possible or desirable, accessing mastery in other ways, however small, could help homebound people to preserve the ideal theorized state of residential normalcy.

Regardless of their situation, all study participants suggested that trying to maintain a positive, determined attitude was key to surviving the experience of being homebound. There is increasing evidence that holding positive beliefs about one's own aging process is associated with better physical, psychological, and social wellbeing (Nakamura et al., 2022). My findings on the ways in which past life experiences inform resilience and acceptance for homebound people echo those of Cheng et al. (2022), who found that prior addiction and homelessness were linked to gratitude and optimism, even in the face of confinement to the home. However, they also reported that most of their homebound study participants felt isolated, lonely, and depressed. The ubiquity of “staying positive” as an imperative among participants in the current study may reflect societal ageism and neglect of older people’s needs, interests, and personhood, such that even that those who are struggling feel they ought to be grateful not to be in worse situations (Chang et al., 2020). Older people, and especially homebound older people, experience high rates of depression (Choi et al., 2010; Xiang & Brooks, 2017). Common symptoms of depression include diminished sense of self-control and competence (Xiang, An, et al., 2020), experiences that were widespread among participants in my study who depended on assistance from others. Indeed, as people become more homebound (i.e., leaving the home less frequently), the prevalence of depressive symptoms increases (Xiang, An, et al., 2020). Older people who receive home- and community-based services have rates of depression 2.5 times higher than those who do not receive these services, but they access psychiatric services at similar rates, suggesting that many are living with untreated depression (Pepin et al., 2017). Pressure to project gratitude and positivity may contribute to reluctance to seek diagnosis and treatment, exacerbating systemic issues with access to mental health services. Findings on older adults’ orientation towards mental health diagnosis and intervention are inconsistent, with some studies concluding that older people are more likely than younger people to seek help for depression and others identifying high levels of stigma, minimization of symptoms, and avoidance of care (Choi et al., 2022).

In light of these findings, it is important to support homebound people to be independent in ways that are meaningful to them and to feel competent and in control of their lives, while leaving space for them to acknowledge when they are struggling and providing appropriate practical and psychological support. Homebound people are individuals with diverse life experiences and priorities, and retaining a sense of autonomy may be particularly important for them given the daily restrictions they experience. Although receiving home care may be essential to enable them to continue living at home, it also has the potential to exacerbate feelings of powerlessness and dependence. In addition to making it easier for homebound people to go out more frequently, if desired, focusing on the nature of their everyday lives within the home could significantly improve their wellbeing. For example, the CAPABLE program, which involves an occupational therapist, registered nurse, and handyperson working collaboratively with people aging in place to help them achieve their own personal goals for independence, is associated with lasting improvements to functional as well as psychological wellbeing (Breysse et al., 2022). Connection to social relationships for those who value these may also be particularly important, given both the link between isolation and depression and the low rates of technology use and internet access among homebound older people.

Limitations

Although adults of any age were eligible to participate in this study, the youngest participant I was able to recruit was 65 years old. It is therefore difficult to differentiate the findings of this study from more general experiences of aging. The sample also had relatively high education compared to older adults in general, although this is line with the demographics of the Bay Area. In addition, almost all of the participants in this study were White, meaning that the results reflect the experiences of only a subset of the homebound population. Specifically, this study lacks representation of the impact of racism on experiences of being homebound and may reinforce a narrow understanding of culturally determined concepts such as independence and autonomy. Only two study participants shared their home with another person. Homebound people who do not live alone may have very different experiences that are not explored in this study. Finally, although two participants were interviewed twice, most only completed a single interview. Experiences such as acceptance, independence, and resistance might shift over time and be different earlier in a person's trajectory of becoming or adjusting to being homebound; longitudinal work could help shed light on this.

Conclusion

This qualitative study explores practical and emotional experiences of being homebound, contributing to a newly emerging body of research in this area. Homebound participants in this study felt stuck in place, stuck with inadequate help, and stuck with a limited range of choices available to them. In response to these restrictions, they demonstrated tenacity, resilience, and a strong desire to retain their sense of independence. The implications of these findings for clinical practice include the importance of prioritizing autonomy and social connection for homebound people. Understanding the life experiences, needs, and preferences of homebound adults can help us better support them to live less constrained and more satisfying lives.

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Chapter 4 : A qualitative study of the experiences of homebound people during the COVID-19 pandemic

Background

The estimated 1.6 million homebound older people in the United States (US) have been hit particularly hard by the COVID-19 pandemic. Although definitions used in research literature vary, the term “homebound” typically refers to people who are usually unable to leave home without assistance or great difficulty (Qiu et al., 2010). On average, people who are homebound are older and in worse physical, mental, and functional health than their non-homebound counterparts (Ornstein et al., 2015; Wajnberg et al., 2013). Prior to the pandemic they already had much higher mortality rates compared to those who were not homebound (Jacobs et al., 2017; Soones et al., 2017), and age- and health-related risk factors made them more vulnerable to becoming seriously ill and dying from COVID (Dessie & Zewotir, 2021).

The number of homebound adults in the US aged 70 and older more than doubled between 2011 and 2020, mostly driven by a large increase from 2019 to 2020 due to the pandemic (Ankuda et al., 2021). By April 6, 2020, shelter-in-place or stay-at-home orders were in place across 42 states and the District of Columbia (Lyu & Wehby, 2020), requiring people to stay at home except for outings for exercise, accessing medical care, and working in essential occupations (Dave et al., 2021). Those who were homebound prior to the pandemic reported greater restriction in life space (i.e. never leaving their home or yard) compared to those who were not homebound before the implementation of shelter-in-place orders (Ankuda et al., 2022), suggesting that even people who felt temporarily “homebound” due to the restrictions were still leaving their homes more often than those who were already homebound previously.

Most homebound older adults rely on outside services coming into their homes to provide assistance with personal care, such as washing or dressing, food preparation, cleaning, exercise, and daily health-related needs (Reckrey et al., 2020). Others live with family members or others who provide care for them. During the pandemic, disruptions to all types of care received by homebound people (paid caregiving, family caregiving, and home-based services) were common (Reckrey et al., 2022). Home care worker staffing shortages, challenges with rapidly increasing telehealth capacity, and inadequate personal protective equipment (PPE) increased pressure on agencies and workers as they tried to continue providing care (Franzosa et al., 2021; Sterling et al., 2020). Home care and home health workers were designated as essential workers in most states, and for many this put them in a difficult position; not only could they not shelter in place and work from home, but they also feared transmitting COVID-19 to and between the particularly vulnerable people they worked with (Reckrey et al., 2022; Sterling et al., 2020; Xu et al., 2022).

In spite of these challenges, the COVID-19 pandemic also brought some improvements to home-based services, for the small proportion of homebound people with access to home health care. The CARES Act permitted nurse practitioners, clinical nurse specialists, and physician assistants to certify and order Medicare home health services (CARES Act, 2020; *Home Health PPS | CMS*, n.d.); for many years, only physicians had been permitted to do this. Suspected or confirmed COVID-19 was added to the list of eligible reasons for being homebound, and telehealth and other remotely delivered services could be included as part of a home health plan of care, although they could not be used as substitutes for in-person visits and were not reimbursable (Medicare and Medicaid Programs; Policy and Regulatory Revisions in Response to the COVID–19 Public Health Emergency, n.d.). Some of these access improvements are likely to become permanent, whereas many ended after the public health emergency declaration expired on May 11, 2023. However, only around 40% of homebound people receive at least one episode of home health care each year, and just 11% have access to home-based medical care (Oseroff et al., 2022). As such, for most homebound people, access to healthcare depends on availability of caregiver support and transportation to travel to clinic or hospital settings (Reckrey et al., 2020).

Few existing research publications have explored the impact of COVID-19 on the lives of people who are homebound, and only two asked homebound people themselves about their experiences rather than using indirect data sources. One study conducted in New York City included perspectives from five users of a homebound community service program, as well as program staff (Liu et al., 2021), but their experiences of issues such as physical wellbeing and loneliness varied widely, making it difficult for the researchers to draw conclusions based on their data. A mixed methods study focusing on social isolation and loneliness in the San Francisco Bay Area (Kotwal et al., 2021) examined “open-ended comments” elicited at the end of a quantitative telephone survey; the authors noted the key role of technological proficiency in maintaining connectedness as well as highlighting unmet functional needs during the pandemic. Other recent qualitative studies have used chart reviews to gather indirect information on homebound adults’ experiences (Reckrey et al., 2022; Xu et al., 2022) or interviewed home care workers or home-based primary care clinical staff (Franzosa et al., 2021; Sterling et al., 2020). Of the published qualitative reports on COVID and homebound older adults, five studies were conducted in New York City (Franzosa et al., 2021; Liu et al., 2021; Reckrey et al., 2022; Sterling et al., 2020; Xu et al., 2022) and one in the San Francisco Bay Area (Kotwal et al., 2021).

Investigating the experiences of homebound older adults during the COVID-19 pandemic is not only relevant for the ongoing public health emergency, but may also provide insights for future disasters such as floods, earthquakes, or heatwaves (Kotwal et al., 2021). Unanticipated events that confine people to their homes and limit access to community-based services have a unique, disproportionate impact on those who are already homebound. The aim of this study was to explore the experiences of homebound older adults living in the San Francisco Bay Area during the COVID-19 pandemic.

Methods

This study was designed and conducted following the theory-methods package of grounded theory (Charmaz, 2014). It was approved by the University of California San Francisco Institution Review Board (#18-25363). The overall study aimed to explore experiences of homebound adults living in the San Francisco Bay Area. I recruited and interviewed seven participants before the COVID-19 pandemic began in early 2020 and all research activities at UCSF were suspended. In 2021, I was able to resume research activities but only virtually. Even if all research restrictions were lifted, the vulnerabilities of my participants as well as my own situation made home visits inadvisable. The remaining interviews were conducted by phone or Zoom meeting. I also tried to contact the initial interviewees again for follow-up interviews; I was able to reach and interview two of them. This paper presents findings from the subset of participants (n = 10) whom I interviewed after the beginning of the COVID-19 pandemic.

Homebound people of any age living in the San Francisco Bay Area were eligible to participate in this study. Self-definition as homebound was used instead of existing criteria such as Medicare or Veterans Affairs (VA) eligibility, for several reasons. First, I hoped to reach a wider constituency beyond the minority of homebound people who receive formal home- and community-based services. Second, I aimed to learn from homebound people about how they defined themselves, rather than presenting them with my own definition. I distributed flyers and recruitment emails through community programs and clinical services targeting homebound people, including meal delivery services, home library services, outreach/befriending, and home-based primary care. I used an initial telephone screening protocol to informally assess cognitive and linguistic ability to complete the interview in English, as well as ensuring participants understood the premise of the study. The original interview guide included questions about trajectories of becoming homebound, services and supports received, and sense of community and connectedness to others. For the post-COVID interviews, I added questions about the impact of the pandemic on participants' lives (see Supplement for sample questions).

All interviews were audio recorded and transcribed through an online transcription service. I removed names and identifying details from transcripts and uploaded them to ATLAS.ti qualitative data analysis software (*ATLAS.Ti 22 Mac*, 2022).

I conducted analysis concurrently with data collection, starting with initial open coding to inductively develop a codebook and iteratively editing the tentative codes and definitions as analysis progressed. The next steps in the cycle were focused coding – pursuing the most salient codes and comparing coded data across interviews – and theoretical coding to build a map of the relationships between codes. I wrote reflective memos throughout and discussed these with my doctoral student peers as I worked back and forth through the data, constructing a conceptual understanding of participants' experiences of being homebound during the COVID-19 pandemic. Pseudonyms are used throughout to protect participants' identities.

Results

Sample Characteristics

Table 4.1 Sample demographics

		N=10 n (%)
Age	*Range*	70-94
	Mean (sd)	82 (8)
Gender	*Female*	5 (50%)
	Male	5 (50%)
Race	*White*	10 (100%)
Living alone		9 (90%)
Housing	*Rent*	6 (60%)
	Own	4 (40%)
Education	*Graduate school*	1 (10%)
	College degree	5 (50%)
	Some college	2 (20%)
	High school	2 (20%)
How long homebound	*1-3 years*	7 (70%)
	4-6 years	2 (20%)
	7-9 years	1 (10%)
Paid caregiving	*None*	4 (40%)
	Twice a week	4 (40%)
	4-5 times a week	2 (20%)

Of the 10 participants in this subsample, five were female and five were male. Ages ranged from 70 to 94, with a mean age of 82 years. All ten participants were White. All but one participant lived alone. Six were renting their homes, and four were homeowners. Two participants reported no major health issues; all of the others reported multiple health problems, such as cancer, diabetes, arthritis, and depression. Interview length ranged from 32 to 80 minutes. Table 4.1 summarizes the demographic characteristics of the sample.

Qualitative Findings

For the participants in this study, concerns about exposure to COVID-19 reinforced prior homebound status, meaning participants left home even less frequently than before, and many also reduced their contact with both paid and family/friend caregivers. The consequences of these choices included difficulties managing at home, postponing healthcare and trying virtual alternatives, and experiencing isolation and loneliness.

Risk of COVID-19 reinforced homebound status

All participants considered themselves homebound at the time of the interview, although some were occasionally leaving the house for medical appointments or exercise. Many mentioned their age and medical history in relation to their sense of personal risk:

> Well, I’ve been extremely risk averse because I have type 2 diabetes and I have a stent, who knows whether I needed it, put in a few years ago. So if I got this ailment, I would have a 90 times greater chance of dying that you would. So I thought it best to be very risk averse. (Brian, 80)

Although being older was clearly understood as a risk factor for COVID-19 infection, for some it also made being stuck at home feel harder. Several participants felt keenly that they had few years left to live: “I don’t know, I’m at an age when a month let alone a year counts” (Brian, 80). Others felt that societal ageism and neglect left them in a precarious position during the pandemic:

> Really, this is a desperate time for older people. […] They are being told that it might be easier if you just disappear. I don't feel that there's a support system. There is not a support system that's available. (Rachel, 86)

Most of the study participants were already homebound before the pandemic, but shelter-in-place orders and self-imposed restrictions on outings reinforced this:

> Well, I used to go to movies all the time. But I stopped that before COVID too. But I think what COVID did to me was before COVID, I knew I could do it if I wanted to. But after COVID, I couldn't do it at all even if I wanted to because the movie theaters were closed and things like that. And dining out for lunch, I used to enjoy that. Yeah, but even after COVID it made it permanent, so to speak. (Sarah, 75)

Although one participant felt that staying at home eliminated the need for her to worry about catching COVID-19, because she was able to manage without anyone coming in from the outside, most of the others emphasized that fear was ever-present in their daily lives. One described it as the “dark cloud over my head” (John, 89), and another said, “You know what really has changed is, I think, the fear. It's this constant concern that – of illness” (Rachel). For the older homebound people in this study, fear of their heightened risk of COVID-19 infection and complications, in combination with their existing physical, psychological, and functional restrictions, made them even more confined to their homes than they already were before the pandemic.

The tradeoff: reducing contact with caregivers to avoid exposure

During this time, all participants were receiving less help and support at home than before the pandemic. For most, this was by choice; they felt the risk of exposure to COVID-19 from helpers coming to their homes outweighed the difficulties they had in caring for themselves without assistance. One described this as “the trade-off” – “the consequences are so grave that, we’re talking about something like this, on balance it’s better to give up things […] and avoid the risk” (Brian, 80).

Prior to the start of the pandemic, challenges experienced by participants in relation to care and support included financial pressure, high turnover of agency staff, limits on services provided, and difficulty finding high quality, compatible caregivers. The pandemic exacerbated these issues and added new concerns, with homebound people basing decisions about care on what they knew about their caregivers' circumstances beyond the work they did in their homes. These considerations included how many other clients they had, their family situation, and their social activities, as well as an overall sense of how cautious they were.

For example, Larry, 71, reduced his home help services from six to five days a week, fearing the additional exposure from a second caregiver who had previously been coming once a week. He could not manage with no home help at all, but this compromise helped him feel he was reducing his risk somewhat:

> Because he was seeing other clients, the guy who came once a week. It didn't make sense to have somebody come here one day a week who had other clients. What if he caught the virus from one of his other clients and he came over here suffering from the virus?

Seth, 82, did not want his caregiver to return after she had recovered from COVID-19, fearing the heightened level of risk indicated by this past infection:

> I was without somebody for quite a while, and then got a very nice young woman. She was like her 20s, sweet girl, and hard worker, very nice disposition, but she was near somebody who had COVID, and I think that she tested positive, so that she was out for treatment or whatever, and I said, "That's it, I don't want her back." I don't want to take the risk, so then I was without somebody for a long time.

Others found that services they would still like to receive were not an option; the decision was made not by them but by the service provider or local government agency.

Their personal "trade-off" calculations led them to prefer to continue receiving home support, including personal caregiving, transportation, and primary care. However, in most cases, in-person services had been replaced by phone or online options. For example, Sarah felt that home visits would have been worth the risk for her, assuming adequate PPE was used, but this choice was not available to her:

> But with the COVID it's hard to get volunteers. Even my husband's having trouble getting volunteers to drive him to appointments and stuff. And I have a home care doctor, you know that. But they can't come either.

In some cases, agencies were permitted to provide services, but individual caregivers chose to stop working due to the risk of exposure to the virus:

> So we were all getting along well, and then when the pandemic came, the one with the babies didn't want to come any more, and then the other one didn't want to do that traveling, and so I got down to nobody. (Seth)

Decisions and arrangements related to caregiving were already challenging prior to the pandemic. In the context of COVID-19, the homebound people in this study grappled with new uncertainties around care and the risks of receiving it, and, whether by choice or not, all had had to adjust to daily life with less support.

Postponing healthcare and trying virtual alternatives

Almost all participants described postponing or being unable to access healthcare during the pandemic, although most did not report significant negative health consequences as a result. Attending clinic or hospital appointments was seen as a particularly high-risk activity that was not justifiable except in emergency situations.

> I haven't had a dental checkup for a year now, always waiting for things will get better. So long as the coronavirus cases keep going up and up, I'll just stay at home and wait until at least a good part of the population has received the

> vaccine, and then I'll start doing things that are like eye examination, the dental things. It's not the sort of thing that I need immediately. (John, 89)

> The only service I’ve had trouble with is medical, I should have seen a doctor, I just put it off because I thought going to a hospital or clinic would be the most dangerous circumstance I could undertake, so I just didn’t do it. (Brian)

Only two participants were enrolled in home-based primary care. Both were offered Zoom appointments but had very different experiences of these, with one noting multiple benefits compared to in-person visits and the other unable to access specialist services because she was not able to connect to Zoom. Michael, 81, had very positive experiences of Zoom, describing it as “another reality, or an opportunity to connect to people much more effectively” and even able to “outdo visitation.” He pointed out the specific benefits of virtual primary care appointments:

> We have it both ways. It takes place, I don't have to take a cab or Muni. I do a pre-visit check-in. One time, I take B12 drops, and he said, "Let me look at the label." Can you imagine I brought the label? "You've got to take 25 drops." Now, there is another thing. Patient visits a doctor who might have an affliction that could be contagious to the doctor, to the nurse. This is a wonderful emergence and I think there are spiritual aspects.

Michael had been given a tablet designed specifically for older people, with excellent technical support available; his positive experiences of online connection were likely driven by his relative ease of access to the internet.

By contrast, Sarah needed technical support to fix her computer, but her usual volunteer was no longer allowed to visit, and she struggled to find other help; without the use of Zoom, she could not access physical therapy services. Rachel, who previously relied on her psychologist and derived great benefit from their visits (in a pre-pandemic interview she described herself as “washed clean” after each session), struggled with phone appointments, describing them as “really the decline of everything.” She stated, simply, “You cannot do medicine over the telephone.”

Isolation and connection

Virtual replacements for care and support services were also ubiquitous. The study participants who felt most isolated and frustrated by the lack of in-person services were those who found virtual meetings and telephone calls were an inadequate substitute for face-to-face contact. In general, online streaming for religious services and classes was seen as a helpful replacement for in-person activities and had even increased accessibility compared to pre-pandemic. Several participants referred to a strengthened sense of community and spirituality fostered during the pandemic.

Others were frustrated by the limitations of Zoom and telephone:

> I mean, we can talk on the phone and everything but that's not the same. And neither is Zoom, that's not the same either. And you have such problems with is sometimes and I think that people like to be in the same room, it's easier to talk with people when they're in the same room. (Sarah)

Rachel exemplified the multiple forms of solitude experienced by many participants. She felt isolated and alienated on some level from everyone in her life. Her caregivers, family members, and neighbors all kept their distance from her:

> [My son] has become like a policeman and just keeping us apart and guarding that we don't touch or get too close. He keeps on telling me, "Mom, get back, get back." That kind of ruins the intimacy.

She was also aware that others in her building saw her as a particularly high-risk contact:

> And the other neighbors are afraid of me. Because of the COVID. In the hallway, they're afraid just to pass by me. So right today, I'm not kidding. The people across

> the hall almost avoid me, because I usually go with a helper and my walker, and they are so afraid of the COVID virus that they don't even want to be in the same space. And, of course, never in the same elevator. This has brought about alienation and a loss of friendships.

Others missed “just normal social interaction” (Brian) and physical touch. Even for Sarah, the only participant who did not live alone, being homebound during the pandemic was isolating:

> Before COVID […] I was kind of busy. I mean, people could come to my house and pass through and visit. […] And then with COVID, it got so that nobody comes. And my husband is here but we get on each other's nerves after a while, it's a small apartment so we're always bumping into each other basically.

In general, the homebound participants in this study who were choosing to eliminate or reduce contact with others experienced less distress related to isolation, even if they had previously enjoyed an active social life. They accepted the potential consequences of choosing to reduce contact with other people as part of their decision-making process. However, those who felt that isolation had been imposed on them by others were suffering more; for them, the benefits of continuing to spend time with other people outweighed their concerns about COVID-19 exposure, and they were frustrated not to have the option to make this choice for themselves.

Discussion

In this qualitative study of the experiences of homebound older adults under COVID-19 restrictions, participants described the shifting calculus according to which they balanced risk of exposure against their needs for care and support. Whereas most people in the US who became temporarily “homebound” under COVID-19 shelter-in-place restrictions likely focused on the difficulties of not being able to go out, for homebound people the experience was more complex. Being stuck at home was not new; trying to navigate who they would let into their homes to help them was a fresh and urgent challenge. Aware of their heightened personal risk of complications from COVID-19 due to their age and health status, most homebound older adults in this study reduced and/or postponed their use of services. Virtual alternatives were helpful for some, although others found them to be an inadequate substitute for face-to-face connection.

Disrupted services and support

All participants in this analysis were receiving less care and support than they had prior to the pandemic. Some had reduced their caregiver hours to avoid or reduce their potential exposure to COVID-19, whereas others still wanted services but found they were unavailable, either because agencies had not returned to in-person service provision or because individual caregivers were not willing to work during the pandemic. The two previously published qualitative studies specifically focusing on homebound participants during the pandemic similarly found that many types of services were inaccessible, including help with cleaning and groceries, and needs were left unmet (Kotwal et al., 2021; Liu et al., 2021). In chart review studies analyzing free-text notes from homebound patients' electronic health records, Reckrey et al. (2022) and Xu et al. (2022) described family members taking on care to avoid exposure to paid workers. Unfortunately, most of the participants in this study did not have family members living with them or close by who could take over from their usual paid caregivers. Research on disabled people's experiences during the pandemic emphasizes that the lack of disability-inclusive emergency responses exacerbated existing structural inequities, unmet needs, and access barriers (Jesus et al., 2021; Sage et al., 2022).

Disruptions to care are likely to become increasingly significant in the future, given home care and home health workforce projections. Almost 48,000 home health workers left the home health workforce between February 2020 and February 2021 (*Health Sector Economic Indicators*, 2021), and home care is facing a similar shortfall (Campbell et al., 2021). Qualitative studies of home health and home care workers document the challenging conditions that contributed to this exodus during the pandemic, including the tension between their sense of obligation to vulnerable clients and their own risk of COVID-19 exposure through working and commuting (Sterling et al., 2020; Xu et al., 2022). Many feared both being infected with COVID-19 through their work and exposing their vulnerable clients to potentially life-threatening infection; some lost hours (and therefore pay) because previous clients were too afraid to continue home visits (Sterling et al., 2020; Tyler et al., 2021; Xu et al., 2022). One home health care worker in Sterling and colleagues' study explained: "I feel guilty because since they're not going outside, I know if they catch it, it's because of me. That's my fear going to work." (Sterling et al., 2020). Indeed, the homebound participants in my study both depended on and feared exposure to their care workers. Poor access to PPE and COVID-19 testing exacerbated stress for home care workers and led some to leave their jobs (Tyler et al., 2021).

Home- and community-based service workforce needs are projected to expand by 37% between 2020 and 2030, making direct care (including home care, residential care, and nursing assistants in nursing homes) the fastest growing workforce in the United States (*Health Sector Economic Indicators*, 2021; *Home Health and Personal Care Aides*, n.d.). Increased demand due to population ageing accounts for one million of the projected job openings, while 3.7 million workers are expected to leave the home care workforce. Turnover is high – typically around 65% – due to low pay, difficult and inconsistent working conditions, and few benefits (Holly, 2022; McCall et al., 2021; Spetz et al., 2019). Against the backdrop of an already strained workforce, there is minimal resilience in the home care industry to protect older adults in case of future pandemics or other emergencies. Action on a national level to improve pay and conditions for home- and community-based workers is urgently needed to improve care quality and consistency and to increase the stability of this essential workforce (Lieberman et al., 2021)l.

Postponing healthcare

Alongside reduced access to home-based care and support, many participants had also postponed contact with healthcare services. Most did not report negative consequences, although many noted the limitations of virtual replacements for face-to-face visits with clinicians. Prior to the pandemic, and compared to their non-homebound counterparts, homebound people were more likely to be admitted to hospital, including potentially preventable hospitalizations, and to attend the emergency department (data from 2011-2017) (Oseroff et al., 2022). They were also less likely to have contact with primary and specialist care, suggesting that lack of access to preventive care and responsive outpatient care leads to late presentation and reliance on acute hospital services. Delayed access to care is associated with health complications as well as high costs; in 2015, 11% of Medicare spending was incurred by homebound older adults, although they made up only 5.7% of the Medicare older adult population (Oseroff et al., 2022).

We do not yet have published data on the implications of pandemic-related healthcare delays for homebound older adults, but several studies address the impact on disabled people in general. In the first year of the pandemic, disabled adults were much more likely than adults without disabilities to report delayed medical care and to have had unmet needs for non-COVID-19 medical care and medical care at home from a nurse or other clinician (Akobirshoev et al., 2022). Dental care has also been particularly impacted (Papautsky et al., 2021). Similarly, there is evidence of reduced uptake of cancer screening, though it may be too early to evaluate the full impact of this on diagnosis and outcomes (Wenger et al., 2022).

In developing a theoretical framework of delay of routine care during the COVID-19 pandemic, Shukla and colleagues built on Unger-Saldaña and Infante-Castañeda's 2011 model of help-seeking behavior (Shukla et al., 2022; Unger-Saldaña & Infante-Castañeda, 2011). They found that participants focused more on the risks of contracting COVID-19 than on the risks of delaying healthcare (or benefits of receiving care). Their model centers on two constructs, perceived uncertainty and subjective risk assessment, across two locations – external (others) and internal (self). Availability of alternative options such as telehealth is theorized as a late consideration, only relevant after the assessment of perceived uncertainty and subjective risk. My findings are broadly aligned with this model, with perceived uncertainty exemplified by questions and concerns about caregivers’ risk behaviors, and subjective risk assessment evident in individuals’ evaluations of their personal risk of serious illness from COVID-19 infection as well as their ability to manage safely at home with reduced or no help. However, Shukla and co-authors’ model only addresses access to health-related services in public settings. In relation to homebound people’s decisions about home-based personal care and support, additional factors are at play. The results of my study indicate that feelings about the importance of physical/in-person contact and the suitability (rather than simply the availability) of virtual alternatives are central to decision-making. Additionally, since choices about personal care services affect daily life and wellbeing, the risks of not receiving such care may be more salient compared to the longer-term potential for negative consequences after postponing a single healthcare encounter.

Most homebound people already have reduced access to health and personal care due to lack of home visiting options, issues with transport, and insufficient caregiving support. They were also already in worse physical and mental health on average prior to the pandemic compared to non-homebound people. In light of this, it is especially important that we prioritize improving their access to healthcare, including evaluating any health issues that may have arisen or deteriorated since the beginning of the pandemic and ensuring preventive interventions such as vaccinations and screening are up to date.

Social isolation and connection – in-person and remote

Many participants struggled with isolation related to COVID-19 precautions, particularly due to the suspension of in-person social support services. Online support was seen as an acceptable replacement for some people, although others found it frustrating and isolating. A qualitative study of care delays and avoidance during the COVID-19 pandemic found similarly mixed experiences, with some reporting that telehealth led to better health and access while others found it impersonal and inadequate (Moore et al., 2022). Social connectedness is an important predictor of wellbeing among older adults in general (Sen et al., 2022), and isolation is associated with becoming homebound for community-dwelling older adults (Xiang, Chen, et al., 2020; Yang et al., 2021) and with increased mortality among those who are already homebound (Sakurai et al., 2019). Even prior to the pandemic, homebound older adults experienced higher rates of social isolation, loneliness, and depression compared to similar non-homebound people (Cudjoe et al., 2022; Ezeokonkwo et al., 2021; Qiu et al., 2010). A study conducted with homebound participants during shelter-in-place in the San Francisco Bay Area found that 40% were socially isolated (Kotwal et al., 2021), and in an analysis of National Health and Aging Trends Study data, older adults who were already homebound prior to the pandemic experienced more loneliness during the pandemic than those who had not previously been homebound (Ankuda et al., 2021).

During the pandemic, people of all ages used online meeting platforms such as Zoom to maintain connections while physical interaction with those from other households was limited. Unfortunately, this option was not available to many homebound people. Across the United States, 51% of homebound older adults have no computer, and 28% do not have a cell phone (Ankuda et al., 2021). One service program in New York City had to suspend all of its home-based activities but found that 95% of its clients did not have access to the internet, making it difficult for them to continue providing support (Liu et al., 2021). Other research confirms that challenges with navigating technology and learning new skills are key barriers to care and connection for homebound older people (Ankuda et al., 2022; Kotwal et al., 2021); providers are often unaware of the obstacles faced by their clients, such as lack of devices, poor or nonexistent internet access, and unmet needs for assistance (Kalicki et al., 2021). Interventions including technology training (Gadbois et al., 2022; Jiménez et al., 2021) and tele-delivered behavioral activation and friendly visiting (Bruce et al., 2021; Choi et al., 2020) show promise for improving social connectedness as well as physical function and mental health for homebound older adults. Even simply using text messaging and email is associated with improved wellbeing and reduced self-reported depression among older adults (Sen et al., 2022).

Given the health and wellbeing risks of ongoing social isolation, developing carefully designed and easily accessible online replacements for in-person socialization should be a priority in the future. Helping homebound people connect to the internet could improve their wellbeing in the short term as well as creating a more resilient infrastructure in anticipation of future pandemics. Since decisions about accessing services and support involve individualized risk-benefit calculations, some people will likely continue to prefer in-person interaction, whereas others appreciate the accessibility and reduced exposure risk of online support. Providing options rather than making assumptions about homebound people's preferences could help to safeguard the crucial benefits of social connection for this often-forgotten group.

Limitations

The subsample used for this analysis is small and lacks diversity. It does not represent the experiences of homebound people of color or younger homebound people. In addition, the San Francisco Bay Area is an urban area in California where COVID-19 mitigation measures were especially robust. Homebound people in rural parts of the country and in areas with less stringent COVID-19 restrictions likely had different experiences. Over the course of the pandemic, scientific data and public health strategy evolved quickly; this paper presents a snapshot of the experiences of homebound people at a particular time and place.

Conclusion

This qualitative study of the experiences of homebound older adults under COVID-19 restrictions explores how homebound people made decisions about care at home during the pandemic, addressing an important gap in the literature. Most reduced the home care support they received and avoided using healthcare wherever possible, but many experienced loneliness and unmet needs as a result. The strengths of this study include its focus on an understudied and often undervalued population, and the use of qualitative research methods to allow homebound people the opportunity to tell their own stories. The implications of the results for policy and practice include improvements to home care quality, access to healthcare, and interventions to address isolation and loneliness. These are not only relevant in relation to the COVID-19 pandemic but should also be instructive for future disasters or emergencies.

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Chapter 5 : Discussion

The experiences of homebound people have long been understudied and poorly understood, although they are known to live with complex health and functional needs, inadequate access to services, and poor outcomes. The purpose of this dissertation was to explore what it is like to be homebound, and to contribute to the conceptual literature on both aging in place and being homebound. I aimed to shed light on this often invisible population and to situate their experiences within wider narratives of aging.

In this concluding chapter, I summarize and synthesize findings from each of the three dissertation papers, discuss implications for practice and policy, and recommend areas of focus for future research.

Dissertation Findings

In Chapter 2, I aimed to evaluate and integrate the existing qualitative evidence on experiences of aging in place in the US by conducting a systematic review and meta-ethnography. There were no previous systematic reviews of qualitative studies of aging in place, and I hoped to contribute new theoretical insights to inform future research in this area. My primary finding was that aging in place is a dynamic process driven by tension between threats and agency across three core experiences – identity, connectedness, and place. An individual's sense of agency was shaped by the balance of resources they had access to and the restrictions on their choices. My visual model represents the relationships between these concepts. I also found that aging in place could be tenuous, requiring significant work and resources to cope with unpredictable needs and challenges – not simply passively remaining in a positive and familiar setting. People maintained their experiences of aging in place by changing their mindset, adapting their home environment, and finding new ways to connect with important people. Those who had fewer resources and struggled to address threats to aging in place felt uncertain, isolated, and dislocated.

The published protocol has been cited 19 times since it was published in 2018, and the systematic review paper has been cited 35 times since publication in 2020, hopefully representing a useful contribution to aging-in-place research.

In Chapter 3, I aimed to explore experiences of homebound adults and to build a conceptual understanding of what it means to be homebound. Based on 17 interviews with homebound older adults in the Bay Area, the findings of my grounded theory study show that being *stuck* is at the core of the experiences of being homebound. Participants felt stuck in place, stuck with inadequate help, and stuck with the limited range of choices available to them. Many reported poor experiences with caregiving services and felt their needs were far from being met. In response to feeling restricted in multiple aspects of their lives, homebound people emphasized the ways in which they retained their independence in spite of the challenges they experienced. This enabled them to distance themselves from negative images of aging and being homebound while demonstrating their autonomy and resilience.

This research joins three other qualitative studies on experiences of homebound people published over the past three years (Cheng et al., 2020, 2022; Mickler et al., 2021). After decades with minimal relevant publications, these studies and my dissertation research suggest a positive trend of increasing interest and attention in this area. My findings confirm the conclusions of these recent studies regarding the impact of dependency and poor-quality home care on the lives of homebound people, while contributing detail on the emotional experience of being homebound. This study also provides qualitative support for recent calls for a more nuanced, multifactorial approach to defining homebound status in research studies (Ko & Noh, 2021; Ornstein et al., 2015; Soones et al., 2017).

In Chapter 4, I aimed to explore experiences of homebound people during the COVID-19 pandemic, drawing on a subset of ten interviews conducted after March 2020. Although the pandemic was an especially challenging time for homebound people, whose health and functional status left them at higher risk of serious complications from COVID-19 infection, only two previous studies had asked homebound people directly about their experiences (Kotwal et al., 2021; Liu et al., 2021); one of these included only five homebound participants. While most people around the world felt restricted by being stuck at home during COVID-19 shelter-in-place orders, homebound people were struggling most with decisions about who to allow into their homes. They engaged in a complex process of risk-benefit analyses, weighing risk of infection against their abilities to cope alone or with reduced levels of help at home. Most were offered virtual alternatives to services and support that they had previous received at home; experiences of this were mixed, depending on individuals' preferences, need for connection to others, and technological resources. Although most participants were already homebound before the pandemic, fear of COVID-19 reinforced their confinement to their homes and reduced their already limited access to help and support. Alongside recently published studies on experiences of home care and home health workers during the early phase of the pandemic (Sterling et al., 2020; Xu et al., 2022), this research demonstrates the scale of the challenges faced by homebound people and those who cared for them during the pandemic.

Synthesis of Findings

My rationale for choosing to conduct a systematic review focused on aging in place, prior to undertaken my primary qualitative research on being homebound, was twofold: (1) at the time, there were not enough published qualitative studies on experiences of being homebound to justify a systematic review, and (2) I wanted to construct a conceptual model of aging in place in order to understand the relationship between being homebound and aging in place, a link that has rarely been acknowledged.

The model informed by my systematic review centers around three domains – identity, connectedness, and place – which formed the key experiences of aging in place. I also theorized that the experience of aging in place was defined by repeated threats to the integrity of the three domains, as well as the agency and resources an individual has available to mitigate these threats. There are multiple parallels between this model and the findings of my qualitative study of homebound experiences. First, agency was also central to my qualitative findings. Homebound people emphasized ways in which they retained autonomy over their lives, even when much felt out of their control. This appeared to be particularly important in relation to their sense of identity, allowing them to demonstrate positive character traits that had defined them throughout their lives. Similarly, both the systematic review and qualitative study findings emphasized the significance of connectedness; negative experiences of aging in place or being homebound included isolation and difficulty maintaining connections with others. Finally, experiences of place were essential to both aging in place and being homebound. Even when homebound people's home situations were very difficult, they typically still held deep personal value for them – perhaps increasingly so as they spent more and more time there. Those I interviewed in person typically showed me around their homes and pointed out objects of great meaning to them. Surviving despite challenging home circumstances also served to demonstrate resilience and other positive character traits, again reinforcing the preservation of personal identity.

However, in contrast to the idea of "dynamic tension" that was key to experiences of aging in place in my systematic review, the overwhelming experience of homebound people in my qualitative study was of being stuck. Although some mentioned the nursing home as a hypothetical alternative, most felt trapped where they were and were not considering alternatives to their current living circumstances. In spite of the similarities between their experiences and those of people aging in place in general, their situations represented one extreme of the continuum of aging in place. They were resigned to an experience of place as fixed, narrow, and restrictive, with associated implications for their access to care and connection. Even those with significant financial resources felt constrained by the limited options available to them within their homes and struggled to find consistent and appropriate care.

Within the dynamic tension model, the COVID-19 pandemic could be seen as constituting a major threat to the experiences of homebound people and others aging in place. It had clear effects on connectedness, with almost all in-person opportunities for interaction suspended. Those with greater technological resources or with family close by were generally better able to mitigate this threat. Similarly, people who were able to manage their daily tasks alone could reduce the threat of COVID-19 infection transmitted by home helpers by not letting anyone into their space. Previous studies of aging and disability have explored how receiving paid assistance can transform the home from a private space to a public workspace. For example, Leibing, Guberman, and Wiles (2016) describe the concept of liminal homes, “threatened” spaces; these include situations where people no longer feel certain that they will not have to move in the future, as well as institutionalized home settings through provision of care services. The pandemic similarly shifted prior boundaries between the risks associated with going out and the safety of staying at home, transforming experiences of place.

Taken as whole, the results of this dissertation suggest the usefulness of understanding being homebound as part of a continuum of aging in place, as well as highlighting the ways in which homebound people’s experiences are unique compared to others aging in non-institutional settings. Understanding the ways in which agency positively affects experiences of identity, place, and connectedness may help inform interventions and service design for people aging in place, including those who are homebound.

Implications of the Research Findings

The findings presented in this dissertation have several implications for aging policy and practice. Local and national aging organizations, resources, and policy makers could better serve older people by being more realistic about what aging in place can involve, including both positive and negative aspects such as the possibility of becoming homebound. Providing tangible resources can help older people weather threats to aging in place, alongside support and guidance on maintaining sense of self, connection to others, and positive experiences of place. The importance of preserved autonomy was a constant thread throughout this dissertation. Measures to safeguard autonomy for homebound people could include home care worker training, longer home care visit times – since it may take longer to support someone to complete a task rather than simply doing it for them – and financial assistance that allows flexibility and choice in how it is spent. Although almost all participants in this study felt stuck with limited options, regardless of their circumstances, those with greater financial resources had more freedom to choose the care arrangements and home environment that would work best for them. Homebound people live with many restrictions on their daily activities; their wellbeing may be greatly improved if they are supported to be independent in ways that are meaningful to them and to feel competent and in control of their lives.

Social connection is also an important factor in the health and happiness of many older people, particularly those who are homebound and have become isolated from their communities. The findings of the studies reported here indicate the importance of providing options for social connection and support, whether virtual or in-person, as preferences vary widely. When expanding telehealth and other virtual services, it is essential to fund technological infrastructure and support, as well as maintaining in-person options for those who cannot or prefer not to use virtual care. Organizations supporting low-income homebound people can support them to access subsidies such as the Affordable Connectivity Program, as well as providing assistance with installation and technological support.

There is a clear need to bolster the home care workforce so that care is both more consistent and reliable in “regular” times and more resilient when crises and disasters happen. Planning for future pandemics should include prioritizing supply of PPE for home care workers and clear guidance on safe practices for both workers and clients. Caregivers are truly essential workers, but some states did not recognize them as such during the pandemic (Tyler et al., 2021). They are often forgotten and undervalued, and working conditions are typically very poor; caregiving is low paid, unstable work with few or no benefits such as sick leave. As a consequence, turnover is rapid, and work-rated injury and illness rates are high (Holly, 2022; Spetz et al., 2019). There are few options for home care workers to improve their conditions; unionization is prohibited in many states (Lieberman et al., 2021), and contracting and payment systems are complex. In order to maintain and grow the workforce in the face of huge increases in expected demand over coming years (*Home Health and Personal Care Aides*, n.d.), with large numbers already leaving the profession (*Health Sector Economic Indicators*, 2021), policymakers should urgently consider strategies to boost retention and attract new workers. Targeted policy interventions could include federal funding to increase minimum earnings, standardized training requirements and career development pathways, and lifting restrictions on labor organizing (Chapman et al., 2022; Lieberman et al., 2021; Spetz et al., 2019).

President Biden’s Build Back Better agenda originally included $150 billion in HCBS funding, but unfortunately this was cut during negotiations to pass what became the Inflation Reduction Act of 2022 (H.R.5376 - Inflation Reduction Act of 2022, 2022). Several recent bills have been introduced in attempts to increase funding for and access to HCBS. These include the HCBS Access Act, which would amend the Social Security Act to require every state to cover HCBS, rather than making HCBS an optional program through waivers, and would also provide grant funding for workforce development and family caregiver support (S.762 - HCBS Access Act, 2023). Similarly, the Better Care Better Jobs Act would establish funding for states to plan and execute HCBS expansion and improvement plans (S.2210 - Better Care Better Jobs Act, 2021). The Supporting our Direct Care Workforce and Family Caregivers Act was first introduced in 2021 and reintroduced this year; it includes funding for a national technical assistance center to support direct care workforce and family caregivers, and grants for direct care workforce and family caregiver support (S.2344 - Supporting Our Direct Care Workforce and Family Caregivers Act, 2021; S.1298 - Supporting Our Direct Care Workforce and Family Caregivers Act, 2023). In spite of the many benefits associated with previous Medicaid expansions, these bills are unlikely to find sufficient support in the current divided Congress.

Finally, homebound people already had limited access to healthcare prior to the pandemic; this was likely exacerbated by suspension of home visiting services as well as vulnerable people’s fears about exposure to COVID-19 in healthcare settings. As pandemic-related restrictions continue to be relaxed, we need to assess homebound people for health conditions that may have developed or worsened during the pandemic and provide accessible treatment options.

The COVID-19 pandemic had serious health implications for many older people, but it also led to positive policy changes that had proven elusive for many years, including growth in tele-delivered services and relaxation of barriers to ordering home health care. Before the next major crisis, we must proactively take the opportunity to fund and support services that are essential for the wellbeing of homebound people.

Limitations and Lessons Learned

After reviewing the existing qualitative literature on experiences of being homebound, I made several decisions about the eligibility criteria for this study. Since prior research in this area focuses exclusively on older adults, I planned to include adults of all ages, hoping to shed light on experiences of homebound people who are under 65. I also intended to recruit from a range of sources, focusing particularly on expanding my sample beyond those already receiving home-based primary care. Finally, I hoped to recruit a sample that would be diverse in terms of gender, socioeconomic status, and race and ethnicity. Although the final study sample was balanced in terms of gender and included renters and homeowners with a range of financial circumstances, it is almost entirely White. There are no data available on the demographics of the homebound population of the Bay Area, but it is certainly more diverse than represented in my sample.

Recruitment in general was more difficult than I had anticipated, especially after the onset of the pandemic. I had not fully realized the implications of not being able to work as a registered nurse in the US – I did not have clinical capital to draw on, in contrast to the strong working relationships I had built with clinicians and organizations working with homebound people in London (UK) over my years working in this field. Many people from my target population have limited access to the internet, so online recruitment efforts resulted in minimal success. I also did not have the personal ability to conduct recruitment and data collection in languages other than English, nor the financial resources to employ someone to do so on my behalf. One partnership was particularly fruitful in terms of recruitment, both before and during the pandemic; this organization was a Jewish support service whose clients are mostly White. I learned that successfully recruiting “hard-to-reach” populations requires significant planning and investment, particularly in terms of developing relationships of trust and mutual benefit, and that this is more difficult to do without existing clinical relationships. A community-based participatory research approach, collaborating with homebound people and organizations that support them to address questions that are of particular importance and urgency to them, would likely be more effective in involving a more representative sample of participants and providing meaningful benefits to the community.

I also struggled to recruit younger participants. Although people aged 18 or older were eligible to participate, my youngest participant was 65 years old. The experiences of younger homebound people remain an important unexplored area; finding better ways to include them in research studies would also help to clarify the intersections and distinctions between experiences of aging (in place), disability, and homeboundness.

Finally, this work was funded by small scholarship awards, and I did not have the resources to employ research assistants to participate in the coding and analysis process. I group-coded and discussed several early interviews with doctoral student peers, then I coded the remaining interviews myself. Qualitative research is deeply and unavoidably personal; having a diverse team involved in the research process can help reveal and interrogate biases and provide a wider range of perspectives.

Future Research Directions

The findings of these studies highlight several important areas for future study. Intervention-focused research could explore ways to improve homebound people's sense of agency and competence, as well as strategies to prevent or delay progression to homebound status. Similarly, longitudinal research design could be used to evaluate trajectories from (actively or "successfully") aging in place to becoming homebound, identifying key moments of transition. Taking a longer view of becoming homebound could also shed light on the role of cumulative inequality – the ways in which earlier experiences and exposures interact to make some people at greater risk of becoming homebound and make their experiences more difficult once they become homebound.

In general, it is essential to include and/or focus on younger people who are homebound in future work, as well as greatly increasing representation of geographic and racial and ethnic diversity in the research literature. The findings reported here also support calls for a more nuanced definition of homebound in future studies, encompassing difficulty of leaving the home and need for and access to help, as well as frequency of going out.

Conclusion

My goals in this dissertation were to explore experiences of homebound people in the US and to contribute to the conceptual dialog on aging in place and homeboundness. The findings of the studies reported here provide in-depth analysis of both phenomena and indicate important directions for future policy, practice, and research. People who are homebound embody great determination and strength, in often oppressively restrictive circumstances. They deserve to be treated as competent individuals with rich experiences and clear preferences for how they live their lives. Improving the supports and services available to homebound people, with a particular focus on safeguarding autonomy, could help alleviate the frustration and pain associated with feeling stuck at home.

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