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Out-of-pocket expenses related to aging in place for frail older people: a scoping review

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ABSTRACT

Objective: The objective of this scoping review was to map and describe the available evidence reporting out-of-pocket expenses related to aging in place for older people with frailty and their caregivers.

Introduction: As the global population ages, there has been increasing attention on supporting older people to live at home in the community as they experience health and functional changes. Older people with frailty often require a variety of supports and services to live in the community, yet the out-of-pockets costs associated with these resources are often not accounted for in health and social care literature.

Inclusion criteria: Sources that reported on the financial expenses incurred by older people (60 years or older) with frailty living in the community, or on the expenses incurred by their family and friend caregivers, were eligible for inclusion in the review.

Methods: We searched for published and unpublished (ie, policy papers, theses, and dissertations) studies written in English or French between 2001 and 2019. The following databases were searched: CINAHL, MEDLINE, Scopus, Embase, PsycINFO, Sociological Abstracts, and Public Affairs Index. We also searched for gray literature in a selection of websites and digital repositories. JBI scoping review methodology was used, and we consulted with a patient and family advisory group to support the relevance of the review.

Results: A total of 42 sources were included in the review, including two policy papers and 40 research papers. The majority of the papers were from the United States (n = 18), with others from Canada (n = 6), the United Kingdom (n = 3), Japan (n = 2), and one each from Australia, Brazil, China, Denmark, Israel, Italy, The Netherlands, Poland, Portugal, Singapore, South Korea, Taiwan, and Turkey. The included research studies used various research designs, including cross-sectional (n = 18), qualitative (n = 15), randomized controlled trials (n = 2), longitudinal (n = 2), cost effectiveness (n = 1), quasi-experimental (n = 1), and mixed methods (n = 1). The included sources used the term "frailty" inconsistently and used various methods to demonstrate frailty. Categories of out-of-pocket expenses found in the literature included home care, medication, cleaning and laundry, food, transportation, medical equipment, respite, assistive devices, home modifications, and insurance. Five sources reported on out-of-pocket expenses associated with people who were frail and had dementia, and seven reported on the out-of-pocket expenses for caregivers of people with frailty. While seven articles reported on specific programs, there was very little consistency in how out-of-pocket expenses were used as outcome measures. Several studies used measures of combined out-of-pocket expenses, but there was no standard approach to reporting aggregate out-of-pocket expenses.

Conclusions: Contextual factors are important to the experiences of out-of-pocket spending for older people with frailty. There is a need to develop a standardized approach to measuring out-of-pocket expenses in order to support further synthesis of the literature. We suggest a measure of out-of-pocket spending as a percentage of family income.

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The review supports education for health care providers to assess the out-of-pocket spending of community-dwelling older people with frailty and their caregivers. Health care providers should also be aware of the local policies and resources that are available to help older people with frailty address their out-of-pocket spending.

Keywords: aging in place; frailty; older adult; out-of-pocket expenses; scoping review

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Introduction

Improving the care of older people experiencing health and functional changes has become a priority for health care systems globally.[1] The proportion of the population over 65 years of age is growing; it is estimated that by 2050 there will be 1.5 billion older people in the world, an increase from 703 million in 2019.[2] Generally, people are living longer and more often have chronic health conditions than in the past.[1,3] With these demographic changes, there has been concern among policy-makers that health care costs will grow.[4] Supporting older people to live in the community as they experience health and functional changes has been promoted as a means to avoid preventable hospitalizations incurred due to insufficient support, and to limit health care costs associated with long-term care (LTC).[5-8] The increasing interest in supporting older people to live in their homes in the community – often referred to as aging in place – as they experience health and functional changes also aligns with literature reporting on the preferences of older people, which demonstrates that they generally prefer to remain at home for as long as possible.[9-11]

There has been a growing imperative in health care literature to understanding the unique situation of older people who have multiple chronic conditions that contribute to functional impairment (ie, those considered frail). Frailty is associated with reduced function, a loss of independence, and need for support, as well as continual decline over time.[12-14] To support this population to remain living in the community, a range of supports are needed, many of which are associated with out-of-pocket expenses – that is, expenses paid by older people and their caregivers without reimbursement.[15] In addition to the health challenges associated with frailty, individuals and their families may experience unanticipated financial burden.[16] Financial considerations contribute to decisions to move to LTC for older people.[17] The costs to enable an older person to live at home may eventually be comparable to the costs of LTC, or financial concerns combined with other factors, such as safety or caregiver strain, may make living at home impossible.[17] While it is essential to consider the sustainability of the health care system as the population ages, it is also important to consider how efforts to support older people in the community contribute to financial burden for them and their family caregivers.[18]

Frailty

Frailty is increasingly recognized as a physiological condition that impacts the health and quality of life of many older adults.[8,13,14] While there is still considerable disagreement in the literature about the operational definition of frailty, it is generally used to refer to people experiencing a loss of capacity to recover after illness, in addition to a higher risk of poor outcomes such as falls, functional decline, mortality, and hospitalization.[8,14,19-21] There is a growing body of literature reporting on how people living with frailty use health care services and community supports, which suggests that those who are frail have higher health and social care costs than those who are not frail.[15,22,23] Frailty prevalence estimates vary significantly; a systematic review conducted in 2012 found that rates of frailty prevalence ranged from 4% to almost 60% of older people aged 65 years and older.[24] Rates varied mainly due to two notable factors: i) the particular characteristics of the population, and ii) the definition of frailty used in the studies. Baseline data from a Canadian longitudinal study found frailty prevalence to be 10.6% in participants over 75 years, with more cases among women and increasing occurrence with age.[25] A recent meta-analysis reported frailty prevalence rates in community-dwelling people 65 years or older in China as 5.9% to 17.4%.[26] We included studies reporting on people over the age of 60 years experiencing frailty because it is the most inclusive age cut-off used to define older adults in the literature.

Out-of-pocket expenses

For this review, out-of-pocket expenses are defined as financial expenses incurred by older adults or

family and friend caregivers to enable frail older people to live well in their homes in the community. Out-of-pocket expenses associated with living well at home include a broad array of services and supports that are related to medical conditions or functional impairment, but are not paid or reimbursed by public health care systems or covered by health insurance. For example, expenses may include assistive devices or over-the-counter medications to address symptoms of health conditions, services such as property maintenance, or essential home modifications to ensure safety when individuals experience functional decline. Literature reporting on the impact of out-of-pocket expenses for people experiencing specific health conditions (eg, cancer, chronic obstructive pulmonary disease, diabetes) also suggests that out-of-pocket spending related to their health conditions impacts their ability to afford basic living expenses such as food and shelter.[27-29] For older people with frailty, who have multiple health conditions that affect their functional abilities, medical and non-medical out-of-pocket expenses are a particularly important issue. Older people are often on fixed incomes, and those experiencing frailty may have few opportunities to engage in paid work.[1] Significant out-of-pocket expenses combined with limited income can contribute to financial insecurity in older people, which in turn can contribute to medication non-adherence, disrupted access to health care, and inability to leave unsafe living environments.[1,27,30]

While there has been a concerted effort by many health and social care leaders to support older people with frailty to live in the community to reduce unnecessary costs associated with LTC,[1,18] the individual-level expenses required to enable living well at home are often not explicitly addressed. In 2010, Johnson and Mommaerts predicted that out-of-pocket spending by older people in the United States would increase over the subsequent 30 years, contributing to significant financial strain.[31]

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Database of Systematic Reviews and Implementation Reports* was conducted and no planned or in-progress systematic or scoping reviews examining the out-of-pocket expenses to support frail older people in the community were identified. While there have been reviews that address the costs associated with supporting older people with frailty in the community, these reviews have approached the subject from the perspective of the health care system and society,[32] and have not considered out-of-pocket expenses borne by individuals and caregivers. Looman and colleagues conducted a review of literature reporting on preventive and integrated care for older people with frailty in the community and reported cost effectiveness from societal and health care perspectives.[33] Apóstolo and colleagues published a systematic review of the effectiveness of interventions to limit the progression of frailty, and included an analysis of health care costs.[34] Lastly, a review by Young and colleagues compared the health care costs of functionally dependent older adults in the community with health care costs of providing care to this population in LTC.[35] However, none of these studies examined the out-of-pocket costs assumed by individuals with frailty and their caregivers. A fourth review explored the economic costs associated with caregiving, and included findings related to out-of-pocket expenses.[16] This scoping review did not discuss the out-of-pocket expenses of caregivers or include information on the out-of-pocket expenses incurred by older people with frailty themselves.[16]

The objective of this scoping review was to map and describe the available evidence reporting out-of-pocket expenses related to aging in place for older people with frailty and their caregivers. An understanding of this literature is important as further synthesis of the available literature can shape policy and practice to better support older people with frailty to continue living in their homes.

Review question

What is the evidence on out-of-pocket expenses associated with aging in place for older people with frailty, and their family and friend caregivers?

Inclusion criteria

Participants

This scoping review considered all research studies and policy papers that included older people experiencing frailty living in community settings, as well as sources that included family and friend caregivers of older people with frailty. Studies that included participants aged 60 years and older, with multiple chronic conditions and functional impairment were included. While our protocol stated we would include studies that employed a measure of frailty, we ultimately decided to broaden our inclusion criteria to studies that described their

population as frail or included an older population with multiple chronic conditions and functional impairment,[36] because the term "frailty" is not consistently defined or applied in the literature.[8]

Concept

This review considered studies that reported on the financial, out-of-pocket expenses incurred by older people living with frailty in the community or by their family and friend caregivers. Out-of-pocket expenses are those that are paid by individuals, and do not include expenses paid by public funding or by third parties such as insurance companies. We only included actual expenses, and did not include studies that estimated financial implications, such as lost income due to unpaid caregiving responsibilities.

Context

This review considered studies that focused on older people living in the community and excluded studies reporting on older people living in LTC or assisted living facilities. Studies conducted in all countries were eligible for inclusion.

Types of sources

For this scoping review, we included published and unpublished original research and policy papers that explored issues related to out-of-pocket spending by frail older adults or their caregivers.

Methods

This review was conducted in accordance with the JBI methodology for scoping reviews,[37] and included input from people with lived experience supporting older people with frailty through two patient and caregiver engagement groups.[38,39] The involvement of stakeholders in scoping reviews aims to provide grounding for the study and foster discussion about potential implications. The patient and caregiver advisory groups in this project contributed to developing the research questions and inclusion criteria, identified keyword synonyms to include in the search, supported the identification of gaps in the body of literature, and generated new ideas about implications of the review.

Search strategy

The search strategy aimed to find both published and unpublished literature (ie, policy papers, theses, and dissertations). A three-step search strategy was used to identify published literature. An initial limited search of MEDLINE (Ovid), CINAHL (EBSCO), and Embase (Elsevier) was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second systematic search using all identified keywords and index terms was then undertaken across all included published literature databases on September 27, 2019. Third, reference lists of included literature were hand searched for additional relevant studies. The search strategy is included as Appendix I.

The databases searched for published literature include: CINAHL (EBSCO), MEDLINE (Ovid), Scopus, Embase (Elsevier), APA PsycINFO (EBSCO), Sociological Abstracts (ProQuest), and Public Affairs Index (EBSCO). MEDLINE (Ovid) replaced PubMed (listed in the protocol) because the final search strategy included two lines that incorporate adjacency searching, which PubMed does not support.

Due to limited resources, only literature published in English or French was considered for inclusion in this review. We restricted our review to studies conducted after 2001 when a seminal definition of frailty was published[21]; this is a deviation from the protocol.

The search for gray literature was completed on September 27, 2019, and targeted the following websites and digital repositories: Agency for Healthcare Research and Quality, Alzheimer's Association: Alzheimer's Disease and Dementia (US), Alzheimer Society of Canada, Alzheimer's Society (UK), American Nurses Association, Canadian Nurses Association, centers for health evidence, conference proceedings, digital dissertations, DiVA (dissertations and other publications in full text from Nordic Universities), EPPI-Centre, Google Scholar, GrayLIT Network, Gray Literature Bulletin (North West Health Library and Information Services, Liverpool, UK), Gray Literature Report (via New York Academy of Medicine website), Gray Source: a Selection of Web-based Resources in Gray Literature, Index to Theses, Institute for Health and Social Care Research, National Information Center on Health Services Research and Health Care Technology, National Library of Medicine, Netting the Evidence, Networked Digital Library of Theses and Dissertations, New York Academy of Medicine Gray Literature Report NLM Gateway, Policy Hub, Primary Care Clinical Practice Guidelines, ProQuest Dissertations and Theses Databases, PsycExtra, Public Health

Agency of Canada, SIGLE (System for Information on Grey Literature in Europe), and TRIP (Turning Research into Practice).

Study selection

After the search was completed, all citations were uploaded to Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia) and duplicates removed. Two reviewers (from among EM, RG, RMM, JP, MM, LEW, EO, and KJ) independently screened the title and abstract of each citation, and selected studies that met the inclusion criteria. The full-text articles were retrieved and uploaded into Covidence. These studies were then assessed independently by two reviewers (from among those listed above) to determine if they met the study inclusion criteria. Any disagreements between the two independent reviewers at each review stage were resolved by consensus or with a third reviewer. Quality appraisal of selected studies was not conducted, as the standard procedure and aim of scoping reviews is to provide an overview of the literature.[37]

Data extraction

Following the JBI scoping review methodology,[37] data were extracted from included papers by two independent reviewers (from among EM, RG, RMM, JP, MM, LEW, EO, and KJ) using a data extraction tool (Appendix II) developed by the reviewers and refined following a piloting with a small number of studies, and subsequently applied to all included studies. Categories of out-of-pocket expenses were refined throughout the data extraction process to ensure all extracted data were accounted for. Any disagreements that arose between the reviewers were resolved through discussion or with a third reviewer.

Data analysis and presentation

Results are reported graphically with tables when possible. The narrative that accompanies the tables further describes the body of literature. The findings of the review are reported in four sections that were determined once the relevant sources were identified to reflect the objectives of the review. The sections are: i) categories of out-of-pocket expenses, ii) measures of combined out-of-pocket expenses, iii) out-of-pocket expenses for select populations, iv) out-of-pocket expenses as outcomes in the evaluation of policies, programs, and services.

Results

Study inclusion

A total of 12,820 titles were identified and uploaded to Covidence for screening. Of these, 3153 were duplicates. At the title and abstract phase, 9667 studies were screened, with 9087 studies found ineligible. There were 580 full-text studies assessed for eligibility through full-text screening, and 538 were excluded (see Figure 1).

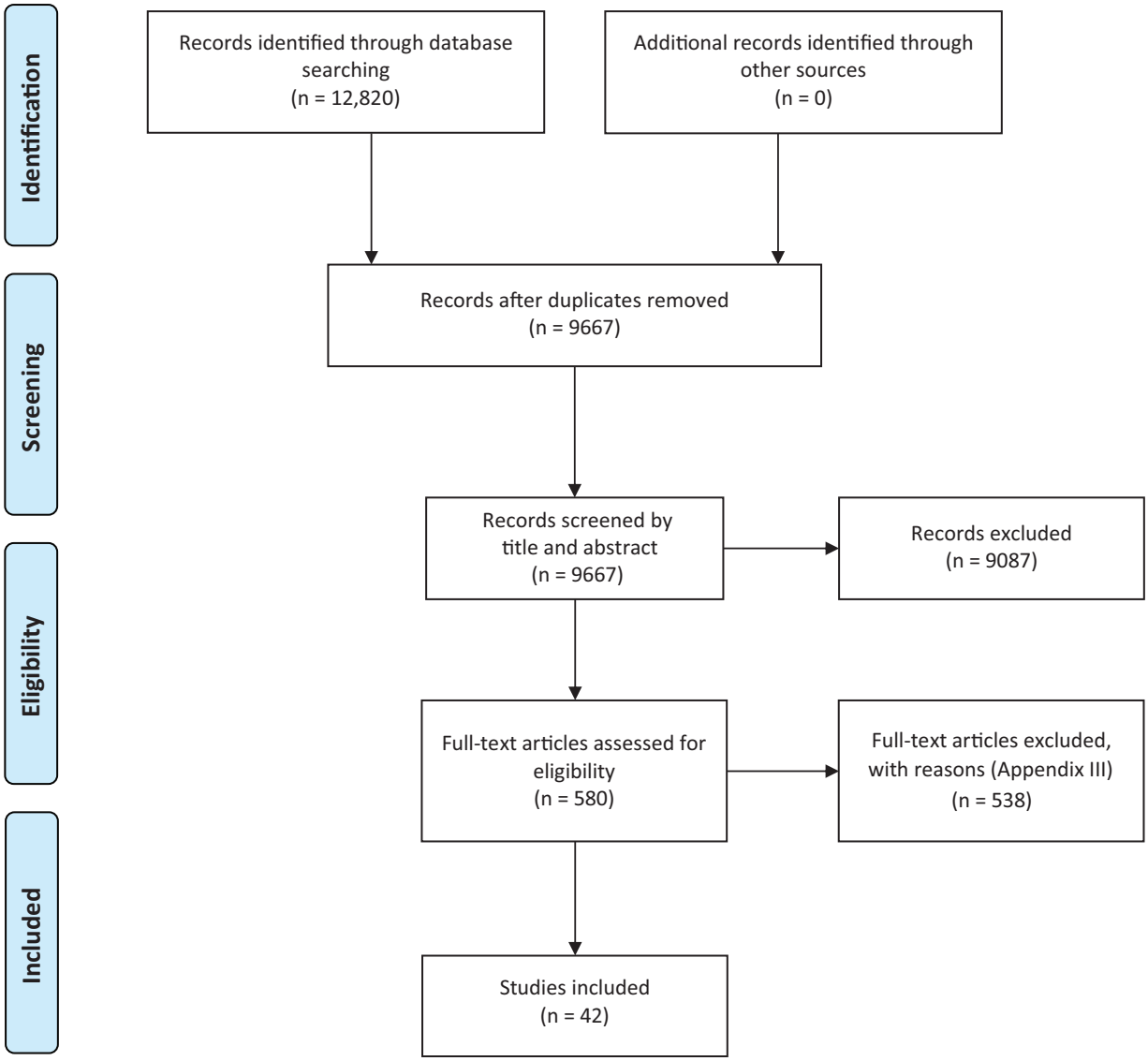
Reasons for exclusion were as follows: not a research study or policy document (173), not reporting on out-of-pocket expenses (139), not including an older population that was frail (193), written in a language other than English or French (17), and not set in the community (10). Six citations were not available as full text through our libraries or after contacting the authors. Detailed information on the reason for exclusion of each article can be found in Appendix III. The resulting 42 articles were included in the review. An examination of the reference lists of the included papers did not result in any further literature for inclusion.

Characteristics of included studies

The characteristics of the included sources are presented in Appendix IV. The majority of the papers were from the United States (n = 18).[40-57] Others were from Canada (n = 6),[58-63] the United Kingdom (n = 3),[64-66] Japan (n = 2),[67,68] and one apiece from Australia,[69] Brazil,[70] China,[71] Denmark,[72] Israel,[73] Italy,[74] The Netherlands,[75] Poland,[76] Portugal,[77] Singapore,[78] South Korea,[79] Taiwan,[80] and Turkey.[81] Studies were published across the date range included (2001 to 2019); there did not appear to be any trends in studying this issue over time. Most sources included costs incurred by individuals and their caregivers, but seven reported costs only for caregivers.[50,61,67-69,77,78] Forty articles were journal articles reporting research findings and two were policy papers.[49,72] The included research studies used various research designs, including cross-sectional (n = 18),[40,45,46,48,50,52,54,56,57,66-68,70,71,75,77,79,81] qualitative (n = 15),[42,47,51,55,58,59,61-63,69,73,74,76,78,80] randomized controlled trials (RCTs; n = 2),[60,64] longitudinal (n = 2),[44,53] cost effectiveness (n = 1),[65] quasi-experimental (n = 1),[43] and mixed methods (n = 1).[41]

Review findings

The results of this scoping review are discussed under the follow sections: i) categories of out-of-pocket



Moher D, Liberati A, Tetzlaff J, Altman DG; the PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009;6(7):e1000097

Figure 1: Search results and source selection and inclusion process

expenses, ii) measures of combined out-of-pocket expenses, iii) out-of-pocket expenses for select populations, and iv) out-of-pocket expenses as outcomes in the evaluation of policies, programs, and services.

Categories of out-of-pocket expenses

We categorized the expenses that each source identified, and summarized the findings in Table 1. The categories were developed by consensus of the review team. The most common category of out-of-pocket expense discussed was home care provided by regulated or unregulated providers (n = 16), followed by medication and medication management (n = 12), cleaning and laundry (n = 10), food and meal preparation (n = 9), transportation (n = 8), medical equipment and assistive devices (n = 8), respite care (n = 6),

Table 1: Categories of out-of-pocket expenses related to aging in place for frail older people

Author	Home care	Medication	Cleaning and laundry	Food	Transportation	Medical equipment and assistive devices	Respite	Home modifications	Insurance	Other
Ayalon *et al.* 2008[73]	X									
Barken 2017[58]	X		X		X					Pet care
Barken 2019[59]	X									
Beland *et al.* 2006[60]	X	X	X		X	X				
Bendixen *et al.* 2005[40]					X					
Cassells and Watt 2003[69]			X			X				
Choi *et al.* 2009[41]		X		X		X		X		Utilities
Clark *et al.* 2008[42]		X		X						
Colling *et al.* 2003[43]						X				
de Craen *et al.* 2006[75]				X		X				
Degiuli 2010[74]	X									Vacations
Dosman and Keating 2005[61]			X					X	X	
Flood *et al.* 2005[65]										
Freedman and Spillman 2014[45]	X									
Hanratty *et al.* 2008[66]	X			X						
Klein *et al.* 2004[46]		X								
Kurpas *et al.* 2018[76]		X								Financial and legal services
Leutz *et al.* 2001[47]	X		X						X	Yard maintenance; emergency response systems
Lien and Huang 2017[80]	X							X		
Liu *et al.* 2017[71]										Financial transfers to children
Moore *et al.* 2001[50]	X		X				X			Hair care
Nakabe *et al.* 2019[67]									X	
O'Keefe *et al.* 2001[51]	X		X	X			X			

Table 1: (*Continued*)

Author	Home care	Medication	Cleaning and laundry	Food	Transportation	Medical equipment and assistive devices	Respite	Home modifications	Insurance	Other
Ploeg *et al.* 2017[62]					X					
Ploeg *et al.* 2019[63]	X	X	X		X					
Sambamoorthi *et al.* 2003[52]		X								
Schoenberg *et al.* 2007[53]	X	X					X			Doctor or dental visits
Schwab *et al.* 2003[54]	X		X	X	X	X	X			
Shafir *et al.* 2016[55]					X					Physician access
Sharkey *et al.* 2005[56]		X								
Stuart and Hansen 2006[72]			X	X						
Taylor *et al.* 2001[57]		X								
Veras *et al.* 2008[70]	X	X		X	X	X	X	X	X	Health care specialists
Washio *et al.* 2012[68]	X			X		X	X	X	X	Care plan services
Zencir *et al.* 2005[81]		X								
Total	**16**	**12**	**10**	**9**	**8**	**8**	**6**	**5**	**5**	

home modifications and renovations (n = 5), and insurance (n = 5). Other out-of-pocket expenses that were identified by one or two sources included dental care,[53] emergency response systems,[47] yard maintenance,[47] doctors' visits,[53] financial transfers to family members,[71] pet care,[58] vacations,[74] hair care,[50] health care specialists,[70] financial and legal services,[76] and care planning services.[68]

Home care

Several studies had an explicit focus on the costs associated with home care for older people with frailty, such as the expenses associated with hiring regulated and unregulated care providers to perform various activities of daily living (ADLs). Two studies discussed the costs associated with hiring unregulated migrant home care workers to provide care for older people.[73,74] Both studies indicated that unregulated migrant home care workers were often hired because they cost less than other home care services. However, the expense of their employment impacted the experience of out-of-pocket spending for caregivers forced to balance the costs of care with the desired quality of care. In Israel, Ayalon and colleagues reported from the perspective of social workers who suggested that families found out-of-pocket costs to hire private care providers contributed to the challenges of caring for older people.[73] In Italy, Degiuli reported findings from interviews with family caregivers of older people and discussed expenses associated with hiring migrant nurses and unregulated care providers. Some study participants felt they could not afford "good care,"[74(p.764)] suggesting that good care would require spending more to have care providers come more often.

Freedman and Spillman examined the out-of-pocket costs associated with home care for people receiving public insurance benefits (Medicare and Medicaid) in the United States.[45] They examined the average number of home care hours used by people requiring various levels of assistance and found that those with higher assistance needs not only received more home care but also paid higher amounts in out-of-pocket expenses, such as copayments and added services, than those with lower assistance needs.

Two papers by Barken conducted in Canada reported on a qualitative study of 34 older people receiving home care.[58,59] One paper focused on how older people receiving home care balanced the expectations of family to be involved in their care with the role of care providers, and found that paying out-of-pocket for services lessened negative feelings associated with being a burden on family caregivers.[58] The other paper explored how older people receiving home care experience independence and dependence, and found that paying out-of-pocket for services contributed to feelings of independence.[59]

Medication

Costs associated with medication and medication management were also a focus of many of the included sources. Sambamoorthi *et al.* examined the financial burden of prescription drugs for older people who were enrolled in a publicly funded insurance program in the United States (ie, Medicare and Medicaid), including an analysis of both total and out-of-pocket expenses.[52] They gathered data on out-of-pocket expenses, including copayments, deductibles, and other charges, and found that higher out-of-pocket costs were related to higher levels of functional impairment, lower levels of self-reported health, more comorbid medical conditions, and female gender.

The out-of-pocket costs of medications and medication management were a particular concern when individuals had limited financial resources.[41,42,46,56,76] Drawing from a national database in the United States, Klein and colleagues examined the characteristics of older people who delayed taking a prescribed medication due to cost.[46] They found that people who had more medical illnesses, ADL limitations, or higher levels of mobility impairment were more likely to report delaying medication use due to cost. Similarly, Choi and colleagues examined the experiences of older people with frailty who were also experiencing neglect or self-neglect, and found that they sometimes did not purchase important medication and therefore did not follow the prescribed treatment, and noted costs as one of the reasons.[41]

Sharkey and colleagues also explored issues around individuals restricting medication use due to costs.[56] They collected data on strategies undertaken to decrease medication costs from a sample of homebound older people receiving home-delivered meals in one US state (North Carolina), and found that 96% of respondents had out-of-pocket medication expenses, including copayments, co-insurance, and costs not covered by insurance. The authors reported monthly out-of-pocket spending by level of insurance; those with no drug coverage had a median monthly out-of-pocket medication cost of US$150, those with government coverage had costs of US$6, and those with supplemental drug coverage had costs of US$100. They also found that 20% of the total sample restricted medication use due to cost.

Clark and colleagues examined people who were socioeconomically disadvantaged, and found many had high copayments for medication that contributed to difficultly making payments.[42] However, few participants in the study reported missing medications due to costs, unlike other research reported here. Ploeg and colleagues also found that the costs of medication affected the ability of older adults with multimorbidity to pay for other essentials, and had to be weighed against spending on other necessities.[63] A study by Kurpas and colleagues exploring the experiences of older people with frailty in Poland accessing health care found that the high costs of medication in relation to available resources meant that many older people did not follow their prescribed treatment plan.[76]

Cleaning and laundry

Housekeeping, laundry, and cleaning were expenses frequently not covered by other programs and services.[47,50,51,54,58,60,61,63,69,72] One study conducted in Canada reported that a woman with the financial means to easily pay for such services preferred to pay for them out-of-pocket rather than add to the burden of her family members.[58] Other sources noted out-of-pocket costs for laundry services associated with incontinence,[69] reported actual costs paid for cleaning,[54] and included housekeeping costs in measures of combined out-of-pocket expenses.[50,60]

Food

Several identified sources noted meal delivery services requiring out-of-pocket costs.[51,54,66,68,75] Two studies reported that other costs impacted the ability of people with frailty to pay for food.[41,42] A policy paper from Denmark suggested that the costs associated with eating out at restaurants were one of the few out-of-pocket costs borne by people with frailty in that country.[72] Only one study included the cost of food in a measure of combined out-of-pocket expenses.[70]

Transportation

Transportation expenses included the cost of taxis, public transportation, gasoline/petrol and car insurance, ambulance costs, and paying friends or family members to provide transportation. Bendixen and colleagues examined the experiences of older people with frailty getting out of their homes and included an exploration of related out-of-pocket costs.[40] The authors drew on data from initial interviews with older people participating in a national longitudinal study in the United States. As part of their analysis, the authors reported the frequency that participants wanted to go somewhere but could not due to financial considerations such as the cost of taxis, gasoline/petrol, or other transportation costs. Seven percent of participants who wanted to go somewhere but could not cited transportation costs as the barrier.

Shafir and colleagues explored the experience of home-based primary care for homebound older people in the United States.[55] A key theme that emerged was related to how the program impacted the costs of accessing medical care. Participants suggested that expenses related to transportation to medical appointments could be prohibitive, and that the home-based primary care program, covered by publicly funded insurance, eased the cost burden of accessing health care elsewhere. Ploeg and colleagues explored the experience of managing multiple chronic conditions for older people living in a Canadian community.[62] They conducted interviews to gather the perspective of older people, caregivers, and health care providers. Participants noted that older people with multimorbidity, particularly those living in rural areas, had challenges accessing transportation to attend medical appointments. This was in a context where the participants attended frequent appointments due to their multiple health conditions, thus needed transportation often. Expenses related to transportation, along with expenses such as medication, were noted to impact decisions about how to spend limited resources, and impacted health and quality of life.[63]

Medical equipment and assistive devices

Medical equipment (eg, home oxygen delivery equipment, diabetic testing supplies, incontinence supplies) and assistive devices (eg, mobility aids) were also reported as out-of-pocket expenses. Two studies looked at out-of-pocket expenses related to incontinence specifically and noted the cost of supplies, such as incontinence pads, disposable pads, disposable diapers, disposable bed pads, and disposable gloves.[43,69] Choi and colleagues noted that individuals experiencing neglect often went without cost-prohibitive medical supplies.[41] Out-of-pocket costs for assistive devices included expenses such as purchasing mobility aids (eg, canes, walkers) and hearing and vision aids. de Craen and colleagues described the use of assistive devices by older people in The Netherlands.[75] They found that devices used to support both mobility (43%) and personal care (27%) were often paid for out-of-pocket. Other sources included medical equipment and assistive devices as part of a combined measure of out-of-pocket expenses,[60,70] reported actual costs of medical supplies,[54] and identified expenses for medical supplies not covered by LTC insurance.[68]

Respite

Six studies included out-of-pocket expenses for respite care of older people experiencing frailty.[50,51,53,54,68,70] Such expenses included adult day centers,[51,54,70] short stays in residential care facilities,[68,70] and other unspecified respite care.[50,53,54]

Home modifications

The sources that reported findings related to out-of-pocket expenses for home modifications described renovations or other significant changes to the home that enabled older people with frailty to adapt to changes in function. A study by Lien and Huang asked adult children of older people experiencing frailty in Taiwan about challenges in providing care.[80] They found that the costs of adapting a home were often prohibitive and contributed to unsafe living circumstances for frail older people.[80] Other studies included out-of-pocket expenses related to home modifications as part of combined measures of out-of-pocket expenses,[70] expenses associated with providing an

adult family living service,[61] and the cost of services not covered by LTC insurance.[68] Choi and colleagues noted that costs associated with home repairs (eg, leaking pipes, leaking roofs, broken toilets) sometimes precluded completing the repairs.[41]

Insurance

Two studies from Japan examined out-of-pocket expenses in the context of a country with a national LTC insurance program. Along with identifying expenses that were not covered by insurance, the studies reported expenses such as insurance copayments.[67,68] Washio *et al.* found that caregivers reported being heavily burdened had higher insurance copayments than those with lower levels of burden.[68] Nakabe *et al.* examined out-of-pocket expenses for caregivers of people with dementia by level of care need and found that copayments were related to care-need level, with caregivers of people with higher needs having higher costs.[67] Insurance was also noted as an expense for adult family living programs[61] and for people using social health management organizations.[47] One study included insurance costs in measures of combined out-of-pocket expenses.[70]

Intergenerational financial transfer

One study conducted in China focused explicitly on intergenerational financial transfers. Liu and colleagues examined intergenerational informal support and financial transfers between older people and their children.[71] Through a national survey, data were collected from almost 1700 older people with frailty.

Measures of combined out-of-pocket expenses

Several of the included sources used combined measures that were total spending amounts related to periods of time or types of expenses. Measures of combined out-of-pocket expenses included monthly out-of-pocket medical expenses,[79] monthly caregiving costs,[77] out-of-pocket spending on health care,[44] privately paid expenses,[82] out-of-pocket expenses over two weeks,[60] expenses paid by individuals for health and social services in the 12 months preceding death,[66] annual personal assistance expenditure,[48] annual out-of-pocket spending,[49] and out-of-pocket expenses over the past two years.[53]

Out-of-pocket expenses for select populations

Within the included studies, out-of-pocket expenses for two sub-populations were particularly common: people with dementia who were frail and caregivers of people who were frail.

Out-of-pocket expenses for people with Alzheimer disease and other dementias

Five of the included studies were focused on people with Alzheimer disease or other dementias. Taylor and colleagues reported on the total costs of care for older people with Alzheimer disease and related dementias living in the community, according to a national survey in the United States.[57] They included an analysis of the out-of-pocket prescription drug costs for this population and found that while most costs were higher for people with more severe dementia, out-of-pocket prescription costs were not higher for people with more severe dementia. In contrast, Zencir and colleagues examined costs associated with Alzheimer disease through data collected from 42 people with Alzheimer disease and their caregivers in Turkey.[81] While their analysis focused on total costs that included both direct and indirect costs, they also noted that out-of-pocket costs for medications increased with the severity of Alzheimer disease.

Nakabe and Huang examined the economic burden of dementia in Japan.[67] They specifically collected data about out-of-pocket costs that were not reimbursed by the LTC insurance program. They found that out-of-pocket expenses were related to caregivers' income, the functional ability of the people with dementia, and the age of the people with dementia. For people with dementia with the highest care needs, the average daily costs of care were estimated to be US$352, compared to US$95 for those at the lowest care-need level. A study by Moore and colleagues examined experiences of female caregivers of male veterans with dementia, and categorized data based on the number of limitations in completing ADLs experienced by the older person with dementia.[50] The study found that caregivers of people with more limitations faced higher out-of-pocket expenses. For example, caregivers of people with more than seven limitations reported paying for an average of 19.8 hours of home health care, which resulted in average costs of US$164 per month. Veras and colleagues examined the out-of-pocket expenses of caregivers of people with dementia in Brazil.[70] They found that expenditures varied by severity of disease and the number of other chronic diseases present.

Out-of-pocket expenses for caregivers

Seven studies examined out-of-pocket expenses for family and friend caregivers of older people with frailty. Two studies explored perspectives of caregivers and highlighted areas where caregivers spent significant amounts on the care of older people with frailty, and may benefit from further publicly funded support. Suen and Thang explored the experience of low-income caregivers of dependent older people in Singapore.[78] They noted that while there were government subsidies that kept medical costs low, there were gaps in resources available to support transportation needs. They also identified administrative costs for caregivers, such as paying fees related to having medical certificates sent to necessary authorities. Veras and colleagues conducted a study in Brazil that examined out-of-pocket costs for family caregivers of older people with dementia.[70] The authors found that, on average, caregivers spent 66% of the family's income on costs associated with caring for the person with dementia.

Washio examined factors that contributed to caregiver burden among caregivers of older people receiving regular hemodialysis treatment in Japan.[68] While many of the services received were paid for by Japan's LTC insurance program, the study measured out-of-pocket costs, including copayments, of the insurance program.

Lien and Huang described the experiences of caregiving for intergenerational family members of older people in Taiwan.[80] They found that some families struggled with the costs of supporting frail older relatives, noting costs associated with nutritious food, medical care, and home care. Similarly, Degiuli explored the experiences of caregivers of frail older people and noted expenses related to groceries, utilities, and home care.[74] Moore and colleagues used a national database in the United States to examine the costs incurred by female caregivers of older male veterans with dementia.[50] They found that, on average, caregivers paid more for care when the person with dementia had higher care needs.

In their study examining sources of strain and distress among caregivers of people older than 100 years in Portugal, Brandão and colleagues examined the relationship between monthly out-of-pocket costs and burden.[77] The study reported monthly costs of caregiving, but did not report details on how the money was spent.

Out-of-pocket expenses as outcomes in the evaluation of policies, programs, and services

Another key area of the findings was related to the influence of various interventions on out-of-pocket expenses for older people living with frailty in the community. A summary of these sources can be found in Table 2.

While this review was open to policy papers that described the impact of policies on the out-of-pocket expenses of older people with frailty, we only identified two such sources. They provided information on how policies impact the experiences of people with frailty. Stuart and Hansen provided a description of LTC services for older people with frailty in Denmark.[72] They described how public services and family caregivers work together to provide care for older people with frailty to meet their complex health and social needs, and described the various policies that supported this situation. They noted that older people at times paid out-of-pocket for household cleaning and meals (if they ate outside the home) but generally, public and family resources provided adequate support for them.

The second policy paper was an issue brief by Moon and colleagues that addressed the financial implications of complex health needs of older people in the United States, and proposed a benefit option as part of the Medicare public insurance program to cover home and community services associated with living in the community.[49] The authors noted that older people with complex needs have higher out-of-pocket expenses than those with less complex needs. The next step, according to the authors, is to examine the financial implications of implementing such a program.

Of the seven research studies that reported on the evaluation of programs and services programs, three were conducted in the United States and included discussion of the costs borne by older people with frailty and their caregivers beyond what was covered by publicly funded insurance (ie, Medicare and Medicaid).[47,48,54] Two included studies examined social health maintenance organizations (HMOs), which provided community-based LTC.[47,54] Leutz and colleagues described the experiences of older people using such a program, noting that some people had expenses for services above and beyond what were covered by the program, such as home care, transportation, and yard work.[47] They also described the out-of-pocket costs associated with

Table 2: Summary of sources that discussed out-of-pocket expenses as outcomes in evaluating policies, programs, and services related to aging in place for frail older people

Author Country	Intervention (program/ service/policy)	Brief description	Method of evaluation	Findings related to out-of-pocket expenses
Béland *et al.*[60] Canada	Community-based multidisciplinary teams	Provision of community-based multidisciplinary integrated care	RCT	No difference was found for out-of-pocket expenditures between control and intervention groups
Dosman and Keating[61] Canada	Program	Provision of high-level care for individuals in a home-like environment	Focus groups	Costs incurred for caregivers included insurance payments, safety equipment, and maintenance/repair expenses
Flood *et al.*[65] UK	Program	Community assessments provided by social workers and occupational therapists	Cost comparison	Costs for participants assessed by social workers were higher; however, the difference was significant only to caregivers
Leutz *et al.*[47] US	Social HMO program	Provision of community-based care services	Qualitative interviews	Some people were found to have expenses beyond program coverage (eg, home care, yard work) Described additional out-of-pocket payments associated with the program that varied according to need
Meng *et al.*[48] US	Voucher program	Vouchers used to reimburse personal assistance expenditures	Quantitative survey data	Intervention group had higher expenditures, and those with higher functional impairment had higher service usage
Moon *et al.*[49] US	Policy	Description of financial implications of older adults' complex health needs	Policy analysis	Older people with complex needs have higher out-of-pocket expenses Describes proposed complex care option for Medicare
Parker and Hill[82] UK	Program	Home-based and day hospital rehabilitation	RCT	Cost analysis found no significant difference between total costs of intervention and control groups
Schwab *et al.*[54] US	Social HMO program	Provision of community-based care services	Gathering actual costs	Average annual estimated costs of services were found to be US$4900 out-of-pocket No comparison with group who received social HMO
Stuart and Hansen[72] Denmark	Policy	Description of care services for older people with frailty in Denmark	Policy analysis	Description of how public services and family caregivers cooperate to provide care Note that some out-of-pocket expenses occurred; however, overall sources provided adequate support

HMO, health maintenance organization; RCT, randomized controlled trial.

being part of the social HMO whereby members of the program paid a monthly premium that varied according to their need, as well as copayments for specific services. Schwab and colleagues examined costs associated with a specific social HMO.[54] These authors calculated what it would cost to pay out-of-pocket for each of the services the program offered. The actual costs reported were obtained by surveying service and supply providers in the community, and reflect an average of several responses. They found that the services would cost an average of $4900 out-of-pocket per year, but did not include a comparison to the cost of delivering the service. Also in the United States, Meng and colleagues evaluated the effect of a voucher program on the out-of-pocket expenditures for personal assistance of older people in the community.[48] The study reported on an RCT of a voucher program that reimbursed personal assistance expenditures. The study found that the intervention group had higher expenditures, and that persons with more functional impairment had higher service use than those without.

Two research studies from the United Kingdom examined programs provided by health care professionals that supported older people with frailty in the community. Flood and colleagues compared the costs and outcomes of community assessments led by social workers and occupational therapists.[65] The authors found that costs for participants being assessed by social workers were higher, although the difference was only significant for costs incurred by caregivers. Parker and colleagues conducted an RCT to determine the effectiveness of home-based rehabilitation compared to day hospital rehabilitation for older people, and included a cost minimization analysis of total costs of care after six and 12 months.[64] The cost minimization analysis found no statistically significant differences in the total costs between the intervention and control groups.

In Canada, Béland and colleagues reported on an RCT aimed to determine the effectiveness of an intervention comprised of community-based multidisciplinary teams providing integrated community care to older people with frailty.[60] The authors analyzed the effect of the intervention on out-of-pocket expenditures including ''nursing, homemaker, over-the-counter medication, technical aids, and transport to access health and social services.''[p.370] They found that there were no differences in out-of-pocket expenditure between the control and intervention groups. Also from a Candian context, Dosman and Keating studied the experience of caregivers in an adult family living program.[61] Adult family living programs, also called adult foster care, offer people who are in need of high levels of care a home-like environment in the community where they receive accommodation, food, and other care from a paid caregiver in the caregiver's home. The authors asked people filling the role of caregiver in the program what types of costs they incurred, and found that insurance payments, safety equipment, and maintenance and repair expenses were important to participants.

Discussion

The purpose of this scoping review was to map and describe the evidence on out-of-pocket expenses incurred by older people with frailty, and their caregivers, to support aging in place. We categorized the types of expenses that have been studied and identified unique expenses that individuals may face. We found that people with dementia and caregivers were subgroups that were often explored in relation to out-of-pocket spending for aging in place. The body of literature had few studies that could be compared in terms of research design or outcome measures, so there is limited opportunity for further qualitative or quantitative systematic reviews.

Literature reporting on the out-of-pocket expenses associated with living in the community for people with frailty and their caregivers largely focused on support for the functional changes the person was experiencing, such as home care, housekeeping, transportation, and meal preparation. However, there were also various expenses identified that have not been regularly recognized in health and social care literature, such as dental care, yard maintenance, pet care, hair care, and legal services. Such services and supports contribute to the ability of people with frailty to maintain their safety and dignity as they experience health and functional changes. None of the included studies explicitly examined costs associated with maintaining meaningful leisure activities for people with frailty. Activities such as participating in social gatherings or maintaining hobbies may also be associated with out-of-pocket expenses, and are important for ensuring quality of life for people with frailty.[83,84]

The review revealed that the policy context was particularly important to the experiences of older adults with frailty and their caregivers with out-of-

pocket expenses. While we sought to include policy documents in order to better understand how policies impacted out-of-pocket expenses, only two such documents were ultimately included. There were, however, notable differences between countries in how individuals experienced out-of-pocket expenses that were directly related to the policy context of the country. For example, there is an LTC insurance program in Japan that covers some costs for people with frailty in the community, reflecting the high proportion of older people in that country. There were also several studies conducted in the United States that referenced the public insurance programs (ie, Medicare and Medicaid), and this literature often reported on out-of-pocket expenses not covered by the programs.

Few studies used out-of-pocket expenses as outcomes in the evaluation of health care interventions to support older people with frailty. This was surprising as cost effectiveness is an important consideration in the implementation of such programs. This finding may reflect the focus on health care and societal costs in cost-effectiveness studies. The findings suggest that out-of-pocket spending is important to the experiences of many older people experiencing frailty and their caregivers. Individuals balance various types of costs and benefits when considering where to live. Developing a more robust understanding of out-of-pocket costs for aging in place will support the evolution of health and social care systems that are reflective of the population needs. In future intervention research, it will be important to include out-of-pocket expenses in cost analyses.

The review also revealed that there is no consistent measure of out-of-pocket expenses used in the literature on older people with frailty. While there were several measures of combined out-of-pocket expenses, there was very little overlap in these measures. A standardized approach to measurement would support comparisons across studies, populations, and interventions, as well as provide an opportunity for further systematic review and meta-analysis. The UN Sustainable Development Goals have an indicator related to out-of-pocket spending on health care as a proportion of total income.[85] It may be useful to report out-of-pocket spending for older people with frailty in a similar manner. In this review, Veras and colleagues reported out-of-pocket expenses as a percentage of the family's monthly income,[70] and Moon and colleagues reported yearly out-of-pocket spending by income.[49] These may be important methods to consider for a standardized approach to reporting out-of-pocket expenses.

While we expected the review to identify many studies that included established definitions of frailty, this was not the case. We adopted a broad definition of frailty so we could incorporate evidence from diverse disciplinary and methodological perspectives, and could discuss how various definitions were used in literature reporting on out-of-pocket expenses. Of the included studies, two used an established operational definition of frailty; both Son and colleagues[79] and Brandão and colleagues[77] used the phenotype model.[21] However, most studies that used the term "frail" to describe their population did not refer to a published definition of frailty. This review therefore further reinforces the need for clarification of the term "frailty" in the literature.

Conclusions

The literature demonstrates that out-of-pocket expenses are an important consideration for older people with frailty, and affect their ability to stay in their homes and communities. These expenses have implications for their health and well-being. While many sources noted out-of-pocket expenses related to home care, a variety of sources of expenses were ultimately noted, including those specific to health experiences (eg, medical supplies, medication), and those related to the particular living situation of individuals (eg, transportation, yard maintenance). The experience of out-of-pocket spending varied across countries. Caregivers of older people with frailty experience the effects of out-of-pocket expenses, and older people with dementia have unique needs impacting out-of-pocket expenses.

The review was limited by the inclusion of articles only written in English and French due to finite resources and an inability to translate literature. Limiting our search to sources published after 2001, when a seminal definition of frailty was published, may have unnecessarily limited our findings.

Implications for research

More research is needed on the contextual factors that impact the experiences of out-of-pocket costs for older people, notably the micro-, meso- and macro-level policy context. There is also a need for consensus around reliability, and consistently measuring out-of-pocket expenses so that there can be meaningful

comparisons across research studies, populations, and contexts.

Implications for practice

This review supports the need for nurses and other health care providers to ask about out-of-pocket expenses when working with older people experiencing frailty. It is important for providers to be aware of the contextual factors that contribute to out-of-pocket spending, such as local policies, and also to stay abreast of resources to support people with frailty and their caregivers with out-of-pocket expenses.

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Appendix I: Search strategy

Searches run September 27, 2019

Database	Terms	Records retrieved
CINAHL [EBSCO]	#1 (MH "Frail Elderly") #2 (MH "Frailty Syndrome") #3 (MH "Health Services for the Aged") #4 (frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab* OR multimorbid* OR "multi morbid*" OR "multiple chronic") N3 (elder* OR aged OR geriatric* OR senior* OR "old age" OR "older adult*" OR "older person*") #5 (MH "Community Living+") OR (MH "Assisted Living") #6 (MH "Senior Centers") #7 "at home" #8 "in place" #9 "own home" OR "own homes" #10 community N3 (living OR dwelling) #11 (MH "Economic Aspects of Illness") OR (MH "Economics+") #12 MW "ec" #13 cost* #14 economic* #15 expens* #16 financ* OR fiscal* OR fee OR fees OR price* OR charge OR charges OR expenditure* OR copay* OR "co pay*" OR "cost of living" OR rate OR rates* #17 (#11 OR #12 OR #13 OR #14 OR #15 OR #16) #18 (#3 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10) #19 (#1 OR #2 OR #4) #20 (#17 AND #18 AND #19)	2181
PsycINFO [EBSCO]	#1 (frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab* OR multimorbid* OR "multi morbid*" OR "multiple chronic") N3 (elder* OR aged OR geriatric* OR senior* OR "old age" OR "older adult*" OR "older person*") #2 "at home" #3 "in place" #4 "own home" OR "own homes" #5 community N3 (living OR dwelling) #6 cost* OR economic* #7 expens* #8 (financ* OR fiscal* OR fee OR fees OR price* OR charge OR charges OR expenditure* OR copay* OR "co pay*" OR "cost of living" OR rate OR rates) #9 DE "Health Impairments" #10 DE "Elder Care" #11 (#1 OR #9 OR #10) #12 DE "Home Care" #13 DE "Aging in Place" #14 DE "Independent Living Programs" #15 DE "Assisted Living" #16 (#2 OR #3 OR #4 OR #5 OR #13 OR #14 OR #15) #17 (DE "Economics" OR DE "Behavioral Economics" OR DE "Evolutionary Economics" OR DE "Health Care Economics" OR DE "Neuroeconomics" OR DE "Pharmacoeconomics") #18 (#6 OR #7 OR #8 OR #17) #19 (#11 AND #16 AND #18)	1355

(*Continued*)		
Database	**Terms**	**Records retrieved**
Public Affairs Index [EBSCO]	#1 (frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab* OR multimorbid* OR "multi morbid*" OR "multiple chronic") N3 (elder* OR aged OR geriatric* OR senior* OR "old age" OR "older adult*" OR "older person*") #2 "at home" #3 "in place" #4 "own home" OR "own homes" #5 community N3 (living OR dwelling) #6 cost* OR economic* #7 expens* #8 (financ* OR fiscal* OR fee OR fees OR price* OR charge OR charges OR expenditure* OR copay* OR "co pay*" OR "cost of living" OR rate OR rates) #9 ((ZU "frail elderly")) or ((ZU "frail elderly – medical care") or (ZU "frail elderly – psychology") or (ZU "frail elderly – services for")) #10 (ZU "elder care") or (ZU "elder care – economic aspects") or (ZU "elder care – finance") or (ZU "elder care – government policy") or (ZU "elder care – law & legislation") or (ZU "elder care – moral & ethical aspects") or (ZU "elder care – psychological aspects") or (ZU "elder care – social aspects") or (ZU "elder care – software") or (ZU "elder care – united states") #11 (ZU "aging in place") or (ZU "aging in place – government policy") #12 (ZU "home care of older people") or (ZU "home care of older people – government policy") or (ZU "home care of older people – law & legislation") or (ZU "home care of older people – united states") #13 (ZU "independent living") #14 (ZU "economics") #15 (#6 OR #7 OR #8 OR #14) #16 (#2 OR #3 OR #4 OR #5 OR #11 OR #12 OR #13) #17 (#1 OR #9 OR #10) #18 (#15 AND #16 AND #17)	220
Embase [Elsevier]	#1 'frail elderly'/exp #2 'frailty'/exp OR 'frailty syndrome'/exp #3 'elderly care'/exp #4 (frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab* OR multimorbid* OR 'multi morbid*' OR 'multiple chronic') NEAR/3 (elder* OR aged OR geriatric* OR senior* OR 'old age' OR 'older adult*' OR 'older person*') #5 'community living'/exp #6 'senior center'/exp #7 'at home' #8 'in place' #9 'own home' OR 'own homes' #10 community NEAR/3 (living OR dwelling) #11 (#5 OR #6 OR #7 OR #8 OR #9 OR #10) #12 'cost of illness'/exp #13 'economics'/exp #14 cost* #15 economic* #16 expens* #17 (financ* OR fiscal* OR fee OR fees OR price* OR charge OR charges OR expenditure* OR copay* OR (co NEXT/1 pay*) OR 'cost of living' OR rate OR rates) #18 (#12 OR #13 OR #14 OR #15 OR #16 OR #17) #19 (#1 OR #2 OR #3 OR #4) #20 (#11 AND #18 AND #19)	2622

(*Continued*)

Database	Terms	Records retrieved
MEDLINE [Ovid]	#1 Frail Elderly/ #2 FRAILTY/ #3 exp Health Services for the Aged/ #4 ((frail* or infirm* or impair* or weak* or ill* or fragil* or vulnerab* or multimorbid* or "multi morbid*" or "multiple chronic") adj3 (elder* or aged or geriatric* or senior* or "old age" or "older adult*" or "older person*")).mp. [mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] #5 (#1 or #2 or #3 or #4) #6 exp Community Integration/ #7 exp Community Health Services/ #8 exp Independent Living/ #9 exp Senior Centers/ #10 "at home".mp #11 "in place".mp. #12 "own home".mp. #13 "own homes".mp. #14 (community adj3 (living or dwelling)).mp. #15 (#6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14) #16 exp "Cost of Illness"/ #17 exp Economics/ #18 economics.hw,fx.[hw = subject heading word, fx = floating sub-heading word] #19 (cost* or fiscal*).mp. #20 economic*.mp. #21 expens*.mp. #22 (financ* or fiscal* or fee or fees or price* or charge or charges or expenditure* or copay* or "co pay*" or "cost of living" or rate or rates).mp. #23 (#16 or #17 or #18 or #19 or #20 or #21 or #22) #24 (#5 and #15 and #23)	2747
Sociological Abstracts [ProQuest]	#1 noft((frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab* OR multimorbid* OR "multi morbid*" OR "multiple chronic") N/3 (elder* OR aged OR geriatric* OR senior* OR "old age" OR "older adult*" OR "older person*")) #2 noft("at home" OR "in place" OR "own home" OR "own homes" OR (community N3 (living OR dwelling))) #3 (Cost* OR economic* OR expens* OR financ* OR fiscal* OR fee OR fees OR price* OR charge OR charges OR expenditure* OR copay* OR (co P/1 pay*) OR "cost of living" OR rate OR rates) #4 MAINSUBJECT.EXACT("Economics") OR MAINSUBJECT.EXACT("Health Care Costs") #5 (#1 AND #2 AND (#3 OR #4))	2483
Scopus	#1 (TITLE-ABS-KEY ((frail* OR infirm* OR impair* OR weak* OR ill* OR fragil* OR vulnerab*) W/3 (elder* OR aged OR geriatric* OR senior* OR "old age" OR "older adult*" OR "older person*"))) #2 ((TITLE-ABS-KEY ("at home" OR "in place" OR "own home" OR "own homes") OR TITLE-ABS-KEY (community W/3 (living OR dwelling)))) #3 (TITLE-ABS-KEY (cost* OR economic* OR expens* OR financ*)) #4 (#1 AND #2 AND #3)	1151

Appendix II: Data extraction instrument

Reviewer: _____

Date: _____

Information to be extracted	
Author(s)	
Year of publication	
Citation information	
Origin (country)	
Type of literature (research [include if thesis] or policy document)	
Aim/purpose	
Design/methods	
Study population	
How frailty was defined	
Group that incurred expenses (older person with frailty, family member, etc.)	

Expenses identified:	Category	Details (include details about temporality or time elements)
	Assistive devices and mobility aids	
	Dental care	
	Financial and legal services	
	Home care (regulated or unregulated providers)	
	Home modifications and renovations (grab bars in bathrooms, ramps, chair lifts, etc.)	
	Housekeeping and cleaning	
	Housing	
	Insurance (eg, house, health, car)	
	Medical equipment (eg, oxygen, diabetic testing supplies)	
	Medication and medication management	
	Nutrition	
	Respite	
	Social and leisure activities	
	Transportation	
	Utilities	
	Yard maintenance	
	Other (specify)	
	Other (specify)	

Appendix III: Studies ineligible following full-text review

Reason for exclusion: Not a research study or policy document (n = 173)

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Appendix IV: Characteristics of included studies

Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Ayalon[73] 2008	Israel	Research	Qualitative using focus groups analyzed with grounded theory	31 social workers employed at two agencies	Authors refer to population as frail	''This pilot study addresses a universal social phenomenon of foreign workers of lower socioeconomic status who provide care to more affluent, but frail older adults. . .this study evaluates the advantages and challenges associated with such an arrangement of care from the perspective of social workers.''(p.121)	The social workers found that the out-of-pocket expense of hiring Filipino home care staff was a challenge because it was expensive and a barrier to developing a more intimate relationship.
Barken[58] 2017	Canada	Research	Qualitative using grounded theory; data collected through interviews	Older people over 65 using home care for ongoing support	Receiving home care but not for acute conditions, and had functional limitations	''The purpose of this grounded theory study was to theorize older peoples' experiences at the intersections of formal and family/ friend care arrangements.''(p.92)	Participants noted several costs related to aging in place, including pet care, home care, cleaning, and transportation.
Barken[59] 2019	Canada	Research	Qualitative, data collected through interviews	Older people over 65 using home care for ongoing support	Receiving home care but not for acute conditions, and had functional limitations	''This article considers how older people who are receiving formal and informal support care for themselves and interpret and give meaning to these practices.''(p.521)	Out-of-pocket expenses were discussed in relation to how they contributed to individuals' perceptions of dependence and independence, particularly related to the ability to pay for help.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Béland[60] 2006	Canada	Research	Quantitative, RCT. Intervention is care by a community-based, multidisciplinary team responsible for coordinating health and social care services	Population was over 64 years and living in the community	Authors refer to population as frail and use the Functional Autonomy Measurement System scale	''We conducted an RCT designed to assess a transformation of the organization and delivery of health and social services with intensified community-based interventions for frail elderly persons.''(p.367)	Out-of-pocket expenses included nursing, housekeeping, over-the-counter medication, technical aids, and transport to access health and social services. They did not find any difference between the intervention and control group in relation to out-of-pocket expenses.
Bendixen[40] 2005	United States	Research	Quantitative; survey including assessment of the places they went in a typical week	People over 60 from community senior service agencies or hospital rehabilitation programs	Authors refer to the population as frail, and define it as having difficulty with at least one ADL and having chronic health conditions	To explore several components related to elders getting out beyond the home, including an exploration of places they visit and would like to visit, distances traveled, reasons for decreases in distances traveled, gender differences, and changes over time.	Participants identified several expenses related to transportation, including cost of taxis, gasoline/petrol, and other costs associated with transportation.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Brandão[77] 2017	Portugal	Research	Quantitative; survey through interviews	Children of centenarian parents who are their primary caregiver	Authors identify the population as frail and cite a previous study by the same authors	''Considering that anxiety, depression and caregiving burden are the most common negative outcomes of providing care for a frail older person, this study aims to explore the presence of such symptomatology in a sample of centenarians' offspring who assume the role of main care providers.''(p.985)	Assessed monthly costs of caregiving. 32.6% of respondents had costs less than €300 per month, and 20.9% had costs over €400. Monthly costs were not related to levels of anxiety or depression.
Cassells[69] 2003	Australia	Research	Qualitative; grounded theory using interviews	Spousal caregivers of partners with incontinence living at home	Authors refer to population as frail, and report each participant having incontinence and an additional health condition	''To explore the impact of caring for a spouse who has incontinence in the home context.''(p.609)	They report financial costs of incontinence experienced by caregivers, including medical supplies (eg, disposable pads, condoms, urinal bottle), home modifications (eg, buying a hospital bed), and costs associated with washing laundry.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Choi[41] 2009	United States	Research	Analysis of quantitative and qualitative data collected on initial adult protective services assessment	Neglect cases reported to adult protective services for adults over 60	Authors refer to the population as frail	The purpose of this study was to examine the economic circumstances of elder self-neglect/neglect. This study examined: i) the types of self-neglect/ neglect, including medical and other forms of self-neglect/neglect, and ii) the association between self-neglect/neglect and deficits in individual economic resources as well as inadequate health care and social service programs for the poor.	Found that older people experiencing self-neglect had out-of-pocket expenses related to basic life necessities that they went without.
Clark[42] 2008	United States	Research	Qualitative interviews	Persons 65 years and older who visited one of two primary care groups	Sample had comorbid chronic conditions and functional impairment	''The aim of this study was to describe and contrast perceptions of self-management among socioeconomically vulnerable and nonvulnerable older adults.''[(p.S313)]	People in the vulnerable group had difficulty affording their medication. Some also noted challenges buying food.
Colling[43] 2003	United States	Research	Quantitative, quasi-experimental	Primary caregivers of frail, community-dwelling older people with incontinence	Authors refer to population as frail	''To determine the impact of a form of habit training called Pattern Urge-Response Toileting (PURT) on caregiver-dependent community-dwelling elderly persons.''[(p.117)]	The average costs of incontinent supplies was US$3.03 per day, and US$1106 per year, per person. The authors projected a individual out-of-pocket savings of US$230 per year if one incontinent episode was eliminated per day.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
de Craen[75] 2006	The Netherlands	Research	Quantitative; description of the use of assistive devices	Dutch community-dwelling 85-year-olds in their own homes	Reported disability on the Groningen Activity Restriction Scale	''To assess the home-situation of the oldest old regarding the ownership, use, and need for intervention of assistive devices and community-based services.''(p.199)	Describe the financing of assistive devices, and report that 27% of the devices were paid for out-of-pocket.
Degiuli[74] 2010	Italy	Research	Qualitative interviews	Population composed of family caregivers of older people with disabilities who employ private caregivers	Authors refer to population as frail	To investigate the lived experiences of care of Italian caregivers and ''to identify the different elements that converge in shaping LTC, among them people's ideals and practical understandings of care, and the interplay between families, the welfare state and the care labour market.''(p756–7)	Participants describe challenges with paying for home care, and also mention costs associated with food and medication.
Dellasega[44] 2001	United States	Research	Quantitative; longitudinal through questionnaire	People age 65 and older, being discharged home from community hospital to a rural setting	Authors refer to population as frail, and all have functional impairment	''To examine patterns of use of home care services by frail older adults in rural areas after hospitalization and to explore the relation between use of resources and patient outcomes.''(p.250)	Mean out-of-pocket health care expenses during the first month post discharge for patients was US$110.24 (SD 366.87; range 0–2000) and for caregivers, US$12.31 (SD 27.68; range 0–109).

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Dosman[61] 2005	Canada	Research	Qualitative; focus groups, field notes and caregiver diaries	Caregivers in a program called AFL where caregivers are contracted to provide care to older people in the caregivers' home	Authors refer to population as frail	''To document costs incurred by AFL caregivers to inform the development of public policy to support this residential care option for frail seniors.''[(p.71)]	Expenditures for AFL caregivers included operating costs, such as comprehensive liability insurance, and extra household maintenance and repairs.
Flood[65] 2005	United Kingdom	Research	Quantitative; economic evaluation	People aged 65 and older living in the community	Authors refer to population as frail	''To compare costs and outcomes of occupational therapy-led assessment with social worker-led assessment of older people, in terms of their independence and quality of life.''[(p.47)]	Examined out-of-pocket costs for older people and carers as a proportion of total costs for the occupational therapy and social worker arms, found to be 14% and 17%, respectively.
Freedman[45] 2014	United States	Research	Quantitative, data from the 2011 National Health and Aging Trends Study	People enrolled in public health insurance for those 65 and older (Medicare)	Functional limitations on three or more activities	''We investigated activity limitations and assistance, care resources, and unmet need for a national sample of older adults.''[(p.509)]	Examined the hours of paid care by level of dependence and found significant increases in paid hours for those with high assistance needs, despite public insurance coverage.

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Hanratty[66] 2008	United Kingdom	Research	Quantitative; data from the British Household Panel Survey	Community-dwelling people who died between 1991 and 2003	Limitations on functional ability	''To analyse the use of and payment for health and welfare services in the year before death for decedents in different financial circumstances, and to determine their receipt of relevant illness related state benefits.''(p.248)	Found that people whose health limited their activities were more likely to pay for health and social care services that others.
Klein[46] 2004	United States	Research	Quantitative; data from the Asset and Health Dynamics Among the Oldest Old study	People over 65 living in the community who reported that they delayed or took less medication because of cost	Impaired mobility and number of chronic conditions	''To describe the health insurance, demographic, health, and financial status information of respondents that, because of cost, reported a delay in filling a prescription or took less of a medication than the amount prescribed.''(p.780)	Participants most susceptible to medication delay due to cost were those with poor health, low income, high out-of-pocket medication expenses, and had Medicare coverage only, as well as persons aged 65 to 80 years and African American elders.

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Kurpas[76] 2018	Poland	Research	Qualitative; focus groups	Stakeholders involved in the care of older people with frailty, including frail older adults, healthy older adults, family caregivers, social care workers, and health care professionals	Authors refer to population as frail	''To explore the issues surrounding access to health and social care services for frail older adults, with Polish stakeholders including frail and robust older adults, health care professionals, social care workers and family caregivers.''(p.3)	Participants expressed frustration regarding inequalities characteristic to the current health care system and the financial obstacles to health. They felt that prompt access to specialists was only available to those with financial resources. Participants commented on costs surrounding legal services and medications.
Leutz[47] 2001	United States	Research	Qualitative; semi-structured interviews	People defined as nursing-home eligible receiving services through a social HMO	Authors refer to population as frail	''To show how members of three Social HMOs [health maintenance organizations] use a limited entitlement for community-based LTC to meet their needs and solve their problems.''(p.44)	Describes co-pays for the social HMOs with some discussion of specific costs. Copays increase with the amount of services used; Minimal Users spent little to nothing, Moderate Users spent US$10 to US$180/month, and Higher Users spent more.
Lien[80] 2017	Taiwan	Research	Qualitative; multiple case study using semi-structured interviews	Family caregivers to older people with frailty	Authors refer to population as frail and report Barthel Index score	To explore ''the challenges faced by multiple generations of families caring for older people in order to determine the community needs of such families.''(p.82)	Limited income influenced offspring caregivers' ability to adequately provide care or meet the persons' fundamental needs (eg, appropriate medical care or nutritious foods).

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Liu[71] 2017	China	Research	Quantitative; data from the Chinese Health and Retirement Longitudinal Study	Community-living people 60 years or older with difficulty with ADL	Had limitations in ADL or IADL and were considered disabled	To fill in a gap in the literature ''through focusing on the association between intergenerational transfers and the time spent on informal care provided to disabled elderly persons.''(p.1366)	On average, the younger generation transferred ¥1608.76 yearly to disabled, older family members. Findings showed a significant, negative correlation between the length of informal care and the younger generations' financial transfers.
Meng[48] 2006	United States	Research	Quantitative; data from the Medicare Primary and Consumer-Directed Care Demonstration	Public insurance beneficiaries 65 years or over living with functional disabilities	Functionally impaired based on ADL and IADL scores and indications of ongoing health issues (eg, recent hospitalization, emergency department visits)	To ''estimate the effect of a voucher benefit on the demand for personal assistance by Medicare beneficiaries aged 65 years or older who had functional disabilities.''(p.183)	Both groups (eg, voucher vs. control) spent an average US$4058 per person on personal assistance annually. Nearly 30% of participants spent > US$3000 annually on personal care (annual voucher benefit max is US$250 x 12). The voucher group's mean annual spending was 17% higher than the control group.

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Moon[49] 2015	United States	Policy	Issue brief	Community-dwelling people over 65 who had public insurance	''Significant impairment in physical functioning—some difficulty with two or more activities of daily living''(p.4)	Describes ''the characteristics and needs of Medicare beneficiaries who require complex care, the goals of a new benefit option that could be made available to this population, and a proposed structure that would both improve care and achieve savings.''(p.3)	On average, complex care beneficiaries spent more of their annual income on out-of-pocket expenses (17%) than those without complex needs (7%). Presents mean/median annual out-of-pocket expenses (% of household income) for community-dwelling beneficiaries living with and without complex care needs.
Moore[50] 2001	United States	Research	Quantitative; data from the National Longitudinal Caregiver Study	Informal female caregivers of community-dwelling US male veterans, aged 60 or over with a formal diagnosis of vascular dementia or Alzheimer disease who were not working	Number of ADL limitations	''The purpose of the study was to examine on a national level the informal costs of caring for elderly community-dwelling male veterans with dementia by female caregivers and the relationships between informal costs and disease severity, and between informal costs and dementia problem behaviors.''(p.S219)	Caregivers paid on average US$86 per week out-of-pocket for formal services, or nearly US$4500 annually. Average out-of-pocket costs for weekly formal services included home health care (US$166), respite (US$109), companion (US$71), and hired helper (US$44).

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Nakabe[67] 2019	Japan	Research	Quantitative; online survey	Non-professional caregivers aged 30 years or over of community-living people with dementia	Care need: a measure of need for LTC	''To clarify the microlevel determinants of the economic burden of dementia care at home in Japanese community settings by classifying them into subgroups of factors related to people with dementia and their caregivers.''(p.2)	Includes out-of-pocket expenses of insurance copayments and LTC services not covered by insurance. If the person could complete some ADLs independently (eg, bathing or toileting), expenses were 65% lower.
O'Keeffe[51] 2001	United States	Research	Qualitative; interviews	Older people who met criteria to be admitted to nursing homes but were living in the community	All had a high level of functional impairment	''To expand our understanding of how low-income functionally impaired elderly persons are able to remain in the community.''(p.73)	Several participants in this study were supplementing Medicare-covered services for other formal out-of-pocket services, which were paid for by family members or the individual themselves.
Parker[64] 2009	United Kingdom	Research	Quantitative; two-arm RCT (day hospital rehabilitation vs. home-based rehabilitation)	People in day hospital rehabilitation and home-based rehabilitation who had ongoing health conditions and functional impairment	Nottingham Extended Activities of Daily Living scale	''To test the hypotheses that older people and their informal carers are not disadvantaged by home-based rehabilitation (HBR) relative to day hospital rehabilitation (DHR) and that HBR is less costly.''(p.iii)	There was no significant difference between the two groups' total costs at the six-month or 12-month follow-up points.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Ploeg[62] 2017	Canada	Research	Qualitative; interviews	Community-living people 65 or older with three or more chronic conditions, family caregivers 18 years or older, and community health care providers	Multiple chronic conditions	''To explore the experience of managing [multiple chronic conditions (MCC)] in the community from the perspectives of older adults with MCC, family caregivers and healthcare providers working in a variety of settings.''[(p.1)]	Costs related to transportation to appointments related to their multiple chronic conditions were discussed.
Ploeg[63] 2019	Canada	Research	Qualitative; interviews	Community-living people 65 or older with three or more chronic conditions	Multiple chronic conditions	''To understand the experiences of living with multiple chronic conditions (MCC) from the perspective of community-living older adults with multiple chronic conditions.''[(p.1)]	A theme related to the cost of living with chronic conditions was identified. Participants discussed out-of-pocket expenses related to: transportation/parking and medical appointments, personal support/home makers, and special medications. Participants also discussed how they carefully manage finances due to costs associated with living with multiple chronic conditions.

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Samba-moorthi[52] 2003	United States	Research	Quantitative; data from the Medicare Current Beneficiary Survey Cost and Use	Community-living people aged 65 years or older enrolled in public insurance	Number of chronic conditions and functional limitations	''The present study estimates total and out-of-pocket expenditures for prescription drugs and the burden of these costs in relation to income among the elderly population.''(p.345)	Findings showed that nearly 8% of older Medicare beneficiaries spent >10% of their earnings on prescription medications. On average, persons spent US$720 annually on prescription medications, with a median expenditure of US$465. Out-of-pocket expenses for medications were higher for women and those living with chronic illnesses. Persons with prescription coverage spent US$169 more annually than those without.
Schoen-berg[53] 2007	United States	Research	Quantitative; longitudinal, data from Health and Retirement Study	People who were 65 or over and were living with multiple morbidity constellations	Multiple chronic conditions	The authors ''explore the key financial issues related to the most commonly occurring multiple morbidities, focusing on how specific constellations of illnesses impact out-of-pocket health care expenditures.''(p.423–4)	Findings showed that out-of-pocket expenses increased over time in relation to the number of chronic illnesses persons were living with.

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Author Date	Country	Type of literature	Research design and key methods	Population/ sample	Frailty	Aims	Key findings related to out-of-pocket expenses
Schwab[54] 2003	United States	Research	Quantitative; phone survey	Members of a social HMO who were enrolled in and met the criteria to be eligible to be admitted to a nursing home	Authors refer to population as frail	''To evaluate the affordability and benefits of [Home and Community Based Services (HCBS)],''[(p.356)] within a Social HMO, and ''analyze the costs of duplicating the services of a Social HMO for an individual who is purchasing them independently in the community.''[(p.356)]	On average, older people with frailty not registered in the social HMO would spend US$4900 out-of-pocket annually to purchase home and community-based services to maintain their independence at home.
Shafir[55] 2016	United States	Research	Qualitative; interviews	Older people receiving home-based primary care and their caregivers	Cumulative Illness Rating Scale for Geriatrics scores were provided to indicate level of comorbidity and chronic illness	''To assess and describe the perspectives of homebound patients and their caregivers regarding what represents quality of care in home based primary care to inform the HBPC [home based primary care] development of patient-centered quality indicators for HBPC.''[(p.1622)]	Affordability was recognized as a valuable aspect of receiving medical care at home. Affordability was associated with avoiding transportation costs (eg, to/from the clinic) and few out-of-pocket expenses.

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Sharkey[56] 2005	United States	Research	Quantitative; data from the Medication Management Study	People aged 60 or over who were enrolled in a home meal delivery program	Four or more health conditions	''To determine the extent to which home-bound older people adopt strategies to reduce out-of-pocket prescription medication cost and the factors associated with level of cost-related medication management.''(p.666)	More than 96% of participants described out-of-pocket expenses associated with prescription medications. Reported median monthly expenses were: US$150 (no coverage), US$6 (government coverage), and US$100 (supplemental coverage). Those with more than four chronic conditions were more likely to restrict medication to save money.
Son[79] 2015	South Korea	Research	Quantitative; data from the Living Profiles of Older People Survey	People over the age of 65 living in the community	Defined frailty based on five criteria outlined by Fried,[21] 2001	''To investigate the effect of frailty on medical expenses in elderly Korean patients.''(p.412)	Findings reported average out-of-pocket expenses for three groups as a percentage of their household income: robust persons (5.98%), pre-frail persons (7.49%), and frail persons (10.67%). Between-group differences were statistically significant. Frailty was associated with an increase in out-of-pocket medical expenditures.

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Stuart 2006[72]	Denmark	Policy	Policy analysis	Older people with frailty	Authors refer to population as frail	To provide ''an overview of reforms in LTC initiated in the early 1980s, describes the relationship between elder care in Denmark and the family, and considers implications for U.S. policy.''(p.27)	Polices supporting older people with frailty are discussed, and the authors note there are very few things that individuals have to pay for out-of-pocket, including meals eaten out
Suen[78] 2018	Singapore	Research	Qualitative; interviews	Informal caregivers of dependent, low-income older people	Older people who had functional impairment and were dependent on family members	''To provide a qualitative account of the contextual challenges faced by low-income primary caregivers of dependent elderly, as well as the mosaic of support they rely on in their efforts to generate resources.''(p.164)	Obtaining transportation for check-ups/follow-up appointments was seen as the most financially problematic issue of concern. The means-testing required to obtain financial assistance was also a barrier to receiving assistance.
Taylor[57] 2001	United States	Research	Quantitative; data from the National Long Term Care Survey	Community-living people 65 years or older with Alzheimer disease or related dementia	Multiple health conditions	''To provide information on the total cost of caring for elderly persons living in community settings, including the distribution of cost among different types of care.''(p.S286)	Prescription medications and caregiving are described as out-of-pocket expenses for families.

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Veras[70] 2008	Brazil	Research	Quantitative; questionnaire	Patients being followed by a Neurogeriatrics Outpatient Clinic and their family caregivers	Report by severity of dementia and comorbidity	''To evaluate family expenditure on elderly people with dementia.''(p.88)	Families commit approximately 66% of their income to caring for elderly persons living with dementia. Expenditures varied depending on the stage of dementia (early [75%] and advanced [61%]), and if other chronic diseases were present (approx. 80%).
Washio[68] 2012	Japan	Research	Quantitative; questionnaire	Patients undergoing hospital based hemodialysis and their caregivers	Authors refer to population as frail, and report Barthel Index score	"To investigate factors related to burden among family caregivers of regular hemodialysis patients.''(p.222)	Heavily burdened caregivers spent more on LTC services and non-LTC services as compared to lightly burdened caregivers.

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Zencir[81] 2005	Turkey	Research	Quantitative; survey	People with Alzheimer disease and their primary caregivers	Severity of dementia and functional impairment	''To evaluate the economic impact of Alzheimer's Disease (AD) in Denizli, Turkey.''[(p.616)]	The annual, average overall cost for persons with Alzheimer disease varied from US$1766 to US$4930 per case. Total caregiver cost was the most substantial expense and varied from US$145 to US$2480 per case annually. Daily medication costs and patient care costs increased as cognition declined. Caregiver cost increased in relation to declining cognitive function.

ADL, activities of daily living; AFL, adult family living; HMO, health maintenance organization; IADL, instrumental activities of daily living; LTC, long-term care; RCT, randomized controlled trial