

REVIEW

What are the priorities for research of older people living in their own home, including those living with frailty? A systematic review and content analysis of studies reporting older people's priorities and unmet needs

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Abstract

Background: There is limited evidence regarding the needs of older people, including those living with frailty, to inform research priority setting.

Objectives: This systematic review aimed to identify the range of research priorities of community-dwelling older people living in their own home, including those living with frailty.

Methods: Included studies were from economically developed countries and designed to identify the priorities for research or unmet needs of community-dwelling older people. Studies were excluded if they described priorities relating to specific health conditions. Medline, Embase, PsycInfo and CINAHL were searched (January 2010–June 2022), alongside grey literature. Study quality was assessed, but studies were not excluded on the basis of quality. A bespoke data extraction form was used and content analysis undertaken to synthesise findings.

Results: Seventy-five reports were included. Seven explicitly aimed to identify the priorities or unmet needs of frail older people; 68 did not specify frailty as a characteristic. Study designs varied, including priority setting exercises, surveys, interviews, focus groups and literature reviews. Identified priorities and unmet needs were organised into themes: prevention and management, improving health and care service provision, improving daily life, meeting carers' needs and planning ahead.

Discussion: Many priority areas were raised by older people, carers and health/care professionals, but few were identified explicitly by/for frail older people. An overarching need was identified for tailored, collaborative provision of care and support.

Conclusion: Review findings provide a valuable resource for researchers and health/care staff wishing to focus their research or service provision on areas of importance for older people.

Keywords: research priorities, older people, frailty, unmet needs

Key Points

- Improving health and care for older people is now being prioritised by governments and research funders, and it is important that research efforts focus on areas deemed important by older people.

- Our systematic review identified the range of priorities for research of community-dwelling older people residing in their own homes, including those living with frailty.
- We identified priorities and unmet needs that were organised into the following themes: prevention and management, improving health and care service provision, improving daily life, meeting carers' needs and planning ahead.
- Review findings provide a valuable resource for researchers and health and care staff wishing to focus their research or service provision on areas of importance for older people.

Introduction

An estimated 19% of the United Kingdom population are aged over 65 years [1], with projections predicting an increase to almost one in four (24.2%) by 2038 [2]: a global pattern of growth [3]. The number of years that people are living with illness and disability is increasing [4]. This demographic shift means that there is an ever-increasing demand for health and care services. Improving health and care for older people is now being prioritised by governments and research funders, and it is important that research efforts focus on areas deemed important by older people. There is limited evidence regarding the needs and priorities of older people, including those living with frailty, to inform the prioritisation of research to address their needs.

Initial scoping work identified two existing James Lind Alliance (JLA) priority setting partnerships (PSPs), which identified the priorities of older people: a UK PSP identified priorities for research for those with multiple conditions in later life [5], and a Canadian PSP identified research priorities for older adults living with frailty [6]. Whilst these PSPs provide important insight, they are limited in their applicability to the wider population of older people. Both focus on sub-populations, and the latter has limited generalisability—as the authors note, there was over-representation of people from one city, women and people with a university education. There are no other JLA PSPs that identify the general priorities of older people. We wanted to review the broader literature to assimilate the priorities already identified by and for older people including, but not limited to, older people living with frailty. The primary purpose of our review was to inform the content of a prioritisation survey for older people in the UK. It also provides a useful resource for the international ageing research community.

Aim

Our aim was to identify the range of existing priorities for research of community-dwelling older people residing in their own homes, including those living with frailty, from the perspective of older people themselves, their relatives, and health and social care professionals.

Methods

Our review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO).

We report our methods and findings in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [7].

Search strategy

Before running our final searches, we tested strategies that included frailty terms in an attempt to separately identify the priorities of those living with frailty; however, this narrowed the search output such that important and relevant papers for this population were excluded. Frailty was thus not included as a search term; instead, we distinguished priorities as important to older people living with and without frailty during data extraction (see below). Our final search strategies (by D.A.—see Appendix 1) included terms related to research priorities, older people (limits not specified, based on our understanding that these may not always be defined) and design terms relating to participatory research or priority setting (including systematic reviews as well as individual studies). Searches were limited to the most recent 12-year period at the time of the search (2010–22) to ensure relevance to the current population of older people, as well as contemporary health and care systems. Searches were run in Medline, Embase, PsycInfo and CINAHL.

Reference and citation searching was undertaken for included papers. Completed JLA PSPs were reviewed for eligibility, as were relevant policy and guidance documents (e.g. National Institute for Health and Care Excellence (NICE) guidance), and charity-commissioned reports (e.g. Age UK).

Screening and selection

References were downloaded to EndNote software and then uploaded to Rayyan systematic review software to support efficient screening by the team. Titles and abstracts were screened for eligibility by L.G. and C.B. or N.H. Where there was uncertainty, agreement was reached by consensus discussions.

Deliberately broad inclusion criteria (Figure 1) enabled an iterative approach to agreeing study inclusion. For example, we identified two types of report: those reporting priorities and those reporting unmet needs. We decided to include unmet needs as well as priorities because these could be interpreted as areas where future research would be beneficial. We debated the inclusion of studies specific to dementia: whilst a distinct population, we decided to include studies where the

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Included studies were:

- 1) from economically developed countries with similar provision of health and care to the UK
- 2) identified the priorities for research of community-dwelling older people; and
- 3) were designed to identify priorities, including PSPs.

Excluded studies were those that:

- 1) reported on areas that were not priorities for research (e.g. priorities for health care practices or policy development);
- 2) described the priorities for specific conditions (e.g. chronic kidney disease) that would not be priorities for the wider population of older people; or
- 3) were intervention studies (randomised controlled trials and other designs) that did not aim to identify general priorities for future research.

Figure 1. Study selection criteria.

identified priorities were important to the wider population of older people (e.g. cognitive screening), but we excluded those reporting priorities relevant only to those living with dementia.

Data extraction and management

Following screening and initial selection, full reports of potentially eligible studies were reviewed by C.B., L.G. and N.H. A bespoke data extraction form was used, including a final eligibility check and the following data for extraction: study aim, participant characteristics, study population, methodology, findings (identified priorities/unmet needs), stated implications and quality assessment. Data were extracted from the first 12 papers by L.G., C.B. and N.H., and then discussed to establish consistency. Uncertainties for later papers were reviewed by a second researcher. Extracted data were managed in Excel and papers categorised according to the population—for example, older people with/without frailty and other stakeholders. We identified participant characteristics that ‘might’ indicate frailty (e.g. older people with multiple chronic conditions) in reports where frailty was not overtly specified.

Quality assessment

We did not exclude studies based on an assessment of quality because we did not require precision for analysis. However, a judgement of the quality of included studies was made (where possible) using the Mixed Methods Appraisal Tool (MMAT) [8] to identify strengths and limitations of the existing evidence. This tool allowed concomitant appraisal of quantitative, qualitative and mixed-methods studies: it was therefore suitable for our review. It produced a score between

0 and 1 (or 0–100%), providing a descriptive (rather than categorical) framework of study quality.

Analysis

Data extracted from all eligible papers were imported into NVivo for analysis. Content analysis [9] was used to synthesise the findings: a systematic analytic technique for categorising data and producing descriptive summaries. The extracted priorities or unmet needs were reviewed, condensed and coded into initial themes (L.G.). Coding was reviewed by K.S. and A.F., and themes iteratively revised following discussion. For clarity of reporting, themes were named ‘priority areas’ describing distinct aspects of older people’s health or well-being deemed priorities for future research. Similar priority areas were grouped into domains that sit within overarching macro-themes.

Results

Study selection

Database searches generated 2,509 records, with 15 additional records from public sources. Sixty-four journal articles and 11 reports (identified via other sources) met our eligibility criteria: 75 reports were included in our review (Appendix 2).

Study characteristics

Study characteristics are presented in Table 1.

Seven reports aimed to identify the priorities or needs of older people living with frailty. Twenty-one reports did not overtly specify ‘frailty’, but the sample description inferred relevance to this population—for example, ‘older people

Table 1. Study characteristics.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Bethell 2019 ⁶	Canada	To produce a list of research priorities relevant to the care, support and treatment of older adults living with frailty	James Lind Alliance (JLA) Priority Setting Partnership (PSP)	Yes	Older people with frailty (52, 6)	Older people without frailty (52, 10); those with experience of frailty—friends/relatives/caregivers (154, 54), HSCPs (273)	75%
Davis 2019 ⁶⁵	UK	To consult frail older adults about a recently adopted service, discharge to assess (D2A), and to prioritise service improvements and research topics associated with the design and delivery of discharge from hospital	Focus groups and interviews	Yes	OP aged ≥ 75 with co-morbidity (27)	None	50%
Green 2021 ³⁸	UK	To understand the most important palliative care needs for community-residing older people living with severe frailty	Interviews and survey	Yes	Older people with frailty age ≥ 70 (20)	None	Unable to assess
Ipsos Mori for Age UK 2014 ⁶¹	UK	To provide Age UK with an understanding of, and insight into: (i) commonalities and differences in the day-to-day life experiences of older people living with frailty, (ii) the overarching issues or problems from the point of view of older people living with frailty and (iii) what would help to improve the lives of older people living with frailty	Interviews and focus groups	Yes	Older people with frailty (10)	Carers (2)	Unable to assess
Robben 2011 ¹⁷	The Netherlands	To give an overview of the care-related goals of community-dwelling frail older adults	Questionnaire to identify goals	Yes	Older people with frailty (366)	None	Unable to assess
Stow 2019 ⁸⁷	UK	To synthesise evidence on the end-of-life care needs of people with frailty	Literature review	Yes	Older people with frailty (18,698)	None	Unable to assess
Royal College of Psychiatrists 2020 ⁷⁰	UK	To provide a review of the literature and identify knowledge gaps that further research might usefully fill	Literature review and healthcare case studies	Yes	Older people with mental health problems	None	Unable to assess
Turcotte 2015 ⁷⁷	Canada	To explore participation needs amongst older adults having disabilities as perceived by older adults themselves, their caregivers and the Health and Social Services Centres healthcare providers	Interviews	Not specified, but sample description infers some inclusion of this population	Older people aged ≥ 65 with moderate to severe loss of functional autonomy (11)	Carers (11), HSCPs (11)	50%
Katz 2013 ³²	UK	To consult older people in as wide a range of 'high support need' circumstances as possible, with the aim of producing a model for identifying wants and needs	Interviews	Not specified, but sample description infers some inclusion of this population	Older people aged ≥ 60 with high support needs (23)	None	50%
Evans 2020 ⁷³	England	To investigate how residents in extra care housing schemes make decisions about the changing nature of their care needs and how they negotiate these with care providers	Interviews and observations	Not specified, but sample description infers some inclusion of this population	Older people resident in extra care housing schemes (51)	Managers (7), staff (20), local authority commissioners (2)	75%
Gregory 2018 ⁷¹	Australia	To investigate enduring issues older people face when interacting with healthcare services	Interviews	Not specified, but sample description infers some inclusion of this population	Older people who need support to live at home (7)	Informal carers (8), key informants in aged care sector (11)	50%
Backman 2018 ⁶⁶	Canada	To engage older adults with multiple chronic conditions and their family members in the detailed exploration of their experiences during transitions across health care settings and identify potential areas for future interventions	Narrated photo walkabouts	Not specified, but sample description infers some inclusion of this population	Older people with multiple chronic conditions (6)	Family members (5)	50%

(continued)

Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Webkamigad 2020 ¹⁶	USA, Canada and Australia	To understand the health and social care needs, priorities and preferences of Indigenous older adults (living outside of long-term care settings) with multiple chronic conditions (MCC) and their caregivers	Literature review and workshop	Not specified, but sample description infers inclusion of this population	Older people with multiple chronic conditions (>566)	Carers (>20), HSCPs (>13)	100%
Spiers 2021 ¹¹	UK	To identify what matters to people with multiple long-term conditions and their carers	Secondary analysis of JLA multiple long-term conditions PSP data + review of priorities	Not specified, but sample description infers inclusion of this population	Older people with multiple health conditions (11)	Older people, carers (4), other stakeholders	Unable to assess
Abdi 2019 ⁴⁰	UK	To identify and understand the care and support needs of older people in the UK, focusing on those living at home with chronic conditions	Literature review	Not specified, but sample description suggests some inclusion of this population	Older people with chronic conditions (7871)	None	Unable to assess
Kuluski 2017 ²²	Canada and New Zealand	To understand the factors that help or hinder patient and family engagement in their care	Interviews	Not specified, but sample description infers some inclusion of this population	Older people with complex health needs (112 across groups)	Informal carers	Unable to assess
Parker 2019 ⁵	UK	To identify the top 10 research priorities on multiple conditions in later life from the perspectives of older people, their carers and HSCPs	JLA PSP	Not specified, but sample description infers inclusion of this population	Older people aged ≥ 80 with multiple conditions (77, 27, 4)	Those with experience of multiple conditions in later life: friends/relatives/caregivers (85, 29, 5), HSCPs (192, 82, 10)	75%
Rimmelzwaan 2020 ⁵¹	Netherlands	To explore the care needs and care experiences and the impact of chronic conditions on daily functioning from a patient perspective, in particular, the community-dwelling multimorbid patient	Interviews	Not specified, but sample description infers some inclusion of this population	Older people with multimorbidity (average age 72) (9)	People age <60 with multimorbidity (3)	75%
NICE guideline (NG22) 2015 ⁵⁹	UK	Older people with social care needs and multiple long-term conditions guideline	Guidance document	Not specified, but sample description infers inclusion of this population	Older people with social care needs and multiple long-term conditions	None	Unable to assess
NICE guideline (NG56) 2016 ⁴³	UK	Multimorbidity: clinical assessment and management guideline	Guidance document	Not specified, but sample description infers some inclusion of this population	People living with multimorbidity	None	Unable to assess
Alhusein 2018 ³⁰	Scotland	To explore: (i) the pharmaceutical care needs of older people with sensory impairment who were receiving polypharmacy and (ii) the experiences, attitudes and training needs of community pharmacy personnel regarding the provision of pharmaceutical care to this patient population	Interviews and survey	Not specified, but sample description suggests inclusion of this population	Older people with sensory impairment and polypharmacy (23)	Community pharmacy personnel	50%
Leroi 2021 ³⁵	UK, France, Cyprus	To explore the unmet support care needs (SCNs) from the perspectives of people with hearing and/or vision impairment in dementia (PwD), and their care partners in Europe	Survey, focus groups and interviews	Not specified, but sample description infers some inclusion of this population	Older people with dementia and hearing and/or vision loss (97, 34)	Carers of those with dementia and hearing/vision loss (97, 34)	75%

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Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Bethell 2018 ¹⁰	Canada	To engage persons with dementia, friends, family, caregivers, and health and social care providers to identify and prioritise their questions for research related to living with dementia and prevention, diagnosis and treatment of dementia	JLA PSP	Not specified, but sample description infers some inclusion of this population	People with dementia (7)	Friends/family/caregivers (5), HSCPs (9), other (7)	75%
Kelly 2015 ⁸¹	UK	To identify unanswered questions around the prevention, treatment, diagnosis and care of dementia with the involvement of all stakeholders; and to identify a top 10 prioritised list of uncertainties	JLA PSP	Not specified, but sample description infers some inclusion of this population	People with dementia (64, 2)	Relatives and carers of people living with dementia (1,188, 5), and HSCPs (224, 11), other (68)	75%
Porock 2015 ³⁶	USA	To obtain a consensus of recommendations from people living with dementia and their care partners on priorities for public policy and where research funded by public dollars should be directed	Two-round Delphi technique	Not specified, but sample description infers some inclusion of this population	People with dementia (27, 23)	Carers and supporters of people living with dementia	50%
López-Entrambasaguas 2020 ⁶²	Spain	To explore the perceptions of chronic patients from the day care centre towards subjective health needs that are not being met by the socio-health system	Focus groups	Not specified, but sample description infers some inclusion of this population	Older people aged ≥ 75 (23)	None	75%
National Voices, Age UK, UCL partners—in partnership with NHS England 2014 ⁶⁰	UK	To explore what matters most to older people in order to develop a specific narrative for older people, reflecting the different perspectives and preferences of that population group	Literature review, survey, interviews, focus groups	Not specified, but sample description infers some inclusion of this population	Older people aged ≥ 75 (74)	Health professionals, system leaders, carers and older individuals (43, 28—across all groups)	Unable to assess
Tisminetzky 2017 ¹³	USA	To prioritise research topics relevant to the care of the growing population of older adults with multiple chronic conditions (MCCs)	Survey	Not specified, but topic area infers relevance to this population	None	Experts in MCC practice, research and policy (366)	25%
Best 2017 ²³	UK	To encourage more research, more collaboration and more multidisciplinary approaches, for both urinary and bowel incontinence	Workshop	Unclear	None	Charities' research communities as well as patients and carers	Unable to assess
Academy of Medical Sciences 2018 ¹⁵	International	To summarise the existing research evidence about the burden, determinants, prevention and treatment of multimorbidity, and to identify areas of weakness in which additional data are required	Expert working group and researcher meetings	No	People living with multimorbidity	Experts and researchers	Unable to assess
Signal 2017 ⁴²	New Zealand	To understand patients' perspectives on living with multimorbidity, their views on healthcare and support and what interventions might improve their lives	Interviews and focus groups	No	People living with multimorbidity (younger and older people) (61)	None	50%
Hughes 2016 ⁶⁶	International	To understand how integrated palliative care services respond to patients' needs and problems	Interviews, questionnaires, diaries	No	Palliative care patients (mean age 73) (157)	Not specified	Unable to assess
McGrath 2022 ³¹	Canada	To identify a set of research and/or rehabilitation priorities related to the influence of physical, social, cultural, political and institutional environmental factors on activity engagement for older adults with age-related vision loss	Critical participatory action research	No	Older people aged > 65 with age-related vision loss (8)	None	75%

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Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Gardner 2019 ²⁰	USA	To explore: prevalence of chronic conditions and associated symptoms amongst diverse community-dwelling older adults, the individual and community resources older residents employ to manage and ameliorate these symptoms, and the barriers they face in accessing palliative care and pain management in the community	Interviews	No	Older people aged ≥ 60 with > 1 chronic condition (100)	Social, faith, community providers (41)	25%
Gill 2017 ³³	Canada and New Zealand	To investigate the impact of patient and caregiver limitations on accessing care, including the impact of the built environment	Interviews	No	Older people aged ≥ 50 with > 1 chronic condition (53)	Informal carers (38)	Unable to assess
Van Aerschot 2022 ⁵⁵	Austria, Finland, Slovenia	To examine community-dwelling older adults' and their informal carers' experiences of unmet needs: what kind of unmet needs they have, why and in which ways these needs are left unmet and what would they want to do to improve the situation	Interviews	No	Older people with care needs (age 65–98) (102)	Informal carers of older people (95)	75%
Age UK 2018 ⁵⁴	UK	To report on the support needs of older people	Reporting nationally available data	No	Older people living with unmet care needs	None	Unable to assess
Alves 2019 ³³	Portugal	To gain further insight into the specific types of unmet needs of community-dwelling older individuals with mental health problems, and their caregivers	Interviews and structured questionnaire	No	Older people aged ≥ 65 with mental health needs (436)	Caregivers (110), general practitioners (family doctors)	50%
Stein 2019 ²⁷	Germany	To analyse the distribution of met and unmet needs and their association with depression in old age	Structured needs questionnaire	No	Older people aged ≥ 75 (845)	None	75%
Stein 2020 ⁶⁹	Germany	To explore the relationship between loss experiences and specific unmet care needs in old age	Structured needs questionnaire	No	Older people aged ≥ 75 (998)	None	75%
Alsaeed 2016 ¹⁸	UK	To identify and prioritise issues that are important to older people that would benefit from further research	Workshop	No	Older people aged ≥ 70 (75)	None	50%
Junius-Walker 2019 ²⁵	Germany	To explore what underlying reasons patients have when they assess the importance of their health problems	Comprehensive geriatric assessment and interviews	No	Older people aged ≥ 70 (34)	None	50%
Junius-Walker 2011 ²⁶	Germany	To understand patients' and doctors' perspectives on individual health and treatment priorities	Comprehensive geriatric assessment and survey questions	No	Older people aged ≥ 70 (123)	General practitioners (11)	75%
Herr 2013 ³⁴	France	To identify unmet health care needs and associated factors amongst older people in France	Interviews	No	Older people aged ≥ 70 (2350)	None	75%
Hurley 2013 ⁵²	Australia	To explore access to community-based support services designed to maintain elders in the community for a particular ethnic group	Interviews and focus groups	No	Older people aged ≥ 69 (22, 48)	Service providers (22)	50%
Doolan-Noble 2019 ⁶⁹	New Zealand	To guide funding priorities for the Ageing Well National Science Challenge in New Zealand. Ensuring broad stakeholder engagement was a key focus	Priority setting (roadshows, including group work)	No	Older people aged ≥ 65 (28)	Researchers (57); family members, carers, HSCPs, government agencies, NGO representatives (48)	50%
Burton 2020 ⁸⁰	USA	To increase understanding of the experiences and needs of older LGBT adults when accessing care	Interviews	No	Older people aged ≥ 65 (10)	None	100%

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Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Health and Care Research Wales & Social Care Wales ⁴⁴	Wales	To identify research priorities relating to care and support of older people, on the topic 'How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?'	Priority setting using JLA methods	No	Older people aged ≥ 65 (80)	Carers (60), social care practitioners (126)	Unable to assess
Seniors' Health Research PSP Steering Group, clinical network, Alberta Health Services and JLA 2019 ¹²	Canada	To identify the questions that are most important about seniors' health in the province of Alberta	JLA PSP	No	Older people aged ≥ 65 (219, 66)	Carers (132, 57), partners, friends, family of older people, HSCPs (314, 109, 22)	Unable to assess
Lee 2015 ⁶⁷	Taiwan	To explore the health needs of older Aboriginal people, using a multidimensional instrument	Structured questionnaire	No	Older people age ≥ 65 (90)	None	75%
Vlachantoni 2011 ⁷⁴	UK	To understand the extent and nature of unmet need for social care in later life	Survey	No	Older people age ≥ 65 (12,032)	None	100%
Mickler 2019 ¹⁹	USA	To understand prior research experiences, research engagement strategies, and research topics of interest to older adults without dementia and caregivers of older adults	Interviews	No	Older people age ≥ 65 (13)	Carers for older people (17)	Unable to assess
Cheraghi 2021 ²⁸	Iran (included studies from Iran, Brazil, Germany, Thailand, Poland, Netherlands and England)	To assess the types of needs of the older people using the Camberwell Assessment of Need for the Elderly (CANE) questionnaire	Systematic review of cross-sectional studies and meta-analysis	No	Older people aged ≥ 60 (mean age 78) (2200)	None	Unable to assess
Kowe 2022 ³⁸	Germany	To examine research priorities and views on research involvement with two stakeholder groups: (i) healthy senior citizens as potential future users of care for people with dementia and (ii) family and professional providers of dementia care experiencing the disease as caregivers and service providers	Group discussions	No	Older people aged > 60 (mean age 72) (31)	Family and professional care providers for people with dementia (16)	50%
Dumoulin 2012 ²⁴	Canada	To identify the priorities for future research of older women with urinary incontinence: (i) intervention types and (ii) outcome measures that are most significant to them	Citizens' Jury approach + Nominal Group Technique	No	Older women aged ≥ 60 with urinary incontinence (43)	None	Unable to assess
Browne 2019 ⁶⁴	USA (Hawaii)	To assist community partners identify health and long-term service and support needs and care preferences of kūpuna (older native Hawaiians) and 'ohana (family) caregivers	Interviews, focus groups, survey	No	Older people age ≥ 60 (60 in total across groups)	Family carers, HSCPs	Unable to assess
Gregory 2017 ⁶³	Australia	To synthesise the qualitative literature about perceived experiences of health care for older people who need support to live at home, from the perspectives of older people, carers and health providers	Literature review	No	Older people age ≥ 60	Carers, health providers	Unable to assess

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What are the priorities for research of older people living in their own home?

Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Centre for Ageing Better 2020 ⁵	UK	Report on the State of Ageing in 2020	Commentary piece using routine data	No	Older people	None	N/A
Kalankova 2020 ³⁷	Finland (included studies from UK, EU, USA, Canada, Australia, Japan, Korea, Taiwan)	To synthesise the findings of empirical research about the unmet nursing care needs of older people, mainly from their point of view, from all settings	Scoping review	No	Older people	Informal caregivers/relatives, healthcare professionals	Unable to assess
Schwartz 2022 ⁷⁵	USA	To identify important issues faced by older adults in the South as a prelude to refining Southern Gerontological Society (SGS) research and service priorities and developing its contemporary regional gerontological agenda	Survey	No	Retired individuals (22)	Academics/researchers (41), practitioners (18), students (7), other (20)	50%
Holm 2013 ⁶⁶	Norway	To report a synthesis of older persons' perceptions of health, ill health and their community health care needs	Literature review	No	Older people age ≥60 (331)	None	Unable to assess
Brocklehurst 2015 ²⁹	UK	To establish a PSP to understand what aspects of oral health are considered important and to empower older people to develop the research agenda to improve primary, secondary and tertiary prevention	Priority setting (using JLA methods)	No	Older people aged ≥60 (11)	Carers (6), third sector representatives (e.g. Age UK) (5), clinicians (3), academics (2), other (2)	50%
Dong 2011 ⁷⁸	USA	To examine the cultural views of healthy ageing, knowledge and barriers to services, and perception of health sciences research amongst community-dwelling Chinese older adults in Chicago's Chinatown	Focus groups	No	Older people aged ≥ 60 (78)	None	75%
Lawrencic 2019 ⁶⁵	Australia	A secondary aim was to determine the aspects of ageing research that a representative cohort of older community members felt were important to include in future studies, to ensure community-driven research priorities	Survey	No	Older people aged ≥ 60 (Aborigine community) (227)	Relatives, nurses (acted as proxies to complete the survey, where needed) (12)	75%
Salma 2019 ⁷⁹	Canada	To understand the experiences of healthy ageing in Muslim communities in an urban centre in Alberta	Interviews and focus groups	No	Older people aged ≥ 55 (51)	Community members (9), religious leaders (2) and community service workers (5)	100%
Kneale 2021 ⁷⁶	UK	To understand how older LGBT people experience health and care trajectories in the UK, and to what extent this experience can and should be interpreted as a health inequality compared to heterosexual people and, consequently, a health inequity	Systematic scoping review	No	Older LGBT people	None	Unable to assess
McCann 2019 ⁶⁸	International	To synthesise the best available evidence on the experiences and perceptions of older people who identify as LGBTQ+ regarding their mental health needs and concerns	Literature review	No	Older LGBT people	Not specified	Unable to assess

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Table 1. Continued.

Author/source	Country	Study aim	Study design	Specific to older people with frailty?	Sample description (older people) (N) ^a	Sample description (other) (N) ^a	Quality assessment (MMAT score)
Vélonis 2018 ⁴⁸	Canada	To conduct a rapid assessment of the needs and gaps in health and social services as perceived by residents and service providers, and to ascertain whether these perceived needs and gaps differ by subgroup	Concept mapping and interviews	No	None (although 'seniors' included)	Community members (~144), service providers (~23)	50%
Wald 2015 ⁴¹	USA	To create a geriatric focused acute-care research agenda, highlighting 10 key research questions	Priority setting (using JLA methods)	No	Unclear	Stakeholder organisations' (for older people) members: included HSCPs, family care givers, 'patients' (580)	75%
Lewin 2011 ³⁰	Australia	To develop a community care research agenda to give direction to research across community-based services for older people, for the next 3–5 years. Aimed to identify top 30 research questions	Workshop, Delphi, expert panel	No	Unclear—reported as 'consumers' (6)	Researchers (6), providers (6), funders/programme managers/policy-makers (6), professional organisations (5)	50%
Public Health England 2020 ¹⁴	UK	PHE Healthy Ageing Research Gap Analysis	Delphi—stakeholder surveys and discussions	No	Not specified	Not specified	Unable to assess
Dogra 2017 ²¹	International	A secondary aim of this work was to identify 5-year research priorities and provide information that is relevant for practitioners and other knowledge users concerned with improving the health of older men and women	Delphi technique	No	None	Experts in sedentary time and ageing (15), other (3)	50%
Kaasalainen 2017 ³⁹	Canada	To identify priority areas in education and research for future development with the aim of improving pain management in older persons	Mixed-methods study, based on a modified Delphi approach	No	None	Practitioners (nurses, physicians, psychologists, pharmacists) (8), researchers (7), decision-makers (2)	50%
Alshibani 2020 ⁴⁷	UK (with participants from EU, USA, Australia)	To build a consensus amongst clinicians to determine research priorities for silver trauma (i.e. major trauma consequent upon relatively minor injury mechanisms, commonly seen in older people)	Three-round modified Delphi	No	None	Clinicians	75%
Goris 2015 ²²	USA	To determine community leader perceptions of health-related needs and resources available to older adults	Interviews	No	None	Community leaders (30)	75%

Note: The table is ordered by 'sample description (older people)' with those identified as frail listed first. ^aWhere more than one number is presented, this indicates multiple rounds of consultation (e.g. initial survey, interim prioritisation, workshop). Where no figures are presented, these were unclear or not available in the report

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aged ≥ 80 with multiple conditions'—although frailty cannot be assumed. One study was unclear regarding the sample characteristics but reported a topic that was relevant to older people living with frailty. Forty-six reports were not specific to older people with frailty, but were relevant to older people generally. Sixty-five reports included older people in their sample, whilst other reports included only other stakeholders' (e.g. clinicians, carers) views of older people's priorities or unmet needs. Thirty-one reports focused on the identification of priorities; 44 reported unmet needs.

Many studies did not clearly define the age of their population, describing only the inclusion of 'older people', or they included a wide age range—e.g. ≥ 60 years with no upper limit.

Study designs included JLA PSPs; priority setting using JLA methodology; and a wide range of other methods, including surveys, interviews, focus groups, consensus groups, workshops and literature reviews. Papers included in the literature reviews were distinct from the individual studies included in our review (i.e. not duplicated).

Quality of included studies

Studies that were quality assessed ($n=46$) varied from poor/medium quality ($n=22$) to high/excellent quality ($n=24$). Twenty-nine reports did not easily fit the MMAT scoring approach or there was insufficient information to inform assessment (e.g. secondary analyses, inadequate methods reporting).

Synthesis

Identified research priorities and unmet needs are presented in Table 2. This table displays their frequencies, differentiating between studies focussed on those living with frailty and those without, those that did and did not include older people in their sample, and those reporting priorities or unmet needs.

Where reports were specific to older people living with dementia, we included only the identified priority areas or unmet needs relevant to all older people—for example, education and training, and adapting the home environment; we did not include dementia-specific priorities and unmet needs as these are set out in a UK dementia PSP [10].

Below, we present a thematic summary that includes all priorities and unmet needs; where priorities are those of older people explicitly defined as living with frailty, this is stated.

Prevention and management

The prevention, recognition and management of frailty, or multiple chronic conditions, was an identified priority for many participant groups [5, 6, 11–44]. As well as prevention and management being a broadly described area of concern (for example, general questions around managing symptom or treatment burden [13, 15, 20]), some studies also reported specific areas of health that could be managed better, including oral health [29], incontinence [23–25, 27,

28], pain [5, 37, 39, 40], medication [5, 18, 26, 30, 41–43] and the impact of vision/hearing loss on functioning [14, 17, 26–28, 30–35]. Studies with specific frailty priorities addressed prevention of unnecessary hospital visits [6]; development or use of tools to identify frailty and to appropriately direct treatment and care decisions [6, 13]; contribution of vision/hearing loss to morbidity [17]; and prevention and management of frailty through rehabilitation services, physical activity, diet and nutrition [6].

Improving health and care service provision

Changes to the health and care system

Many reports identified changes to the health and care system that might improve older people's experiences and better meet their needs. Priorities identified for older people living with and without frailty included the following: tailoring healthcare services to meet their needs for care and health service provision [11, 12, 18, 43–47], tailoring services to meet the needs of those who are isolated or without support [6, 48], better integration of health and care services (i.e. 'joined up care') [5, 6, 11, 13, 15, 33, 40, 42, 44, 46–51], improved community and home-based services to support those with chronic conditions or frailty [6, 14, 22, 37, 40, 43, 48, 50, 52–54], improved healthcare delivery [17, 19, 33, 40, 52, 55], novel models of care [13] and improving end-of-life care and addressing palliative care needs [6, 13, 56–58].

Priority areas for non-frail older people included improving transitions of care between hospital and home [12, 18, 41, 50], reducing hospital admission and re-admission rates [5], identifying effective service delivery models for those with complex health and social care needs [59], exploring how to optimise delivery of care models (e.g. comprehensive geriatric assessment) for those with multiple long-term conditions [5], and improving access to and availability of oral health services [29, 34, 37].

Decision-making and care planning

The importance of making shared decisions about care needs and care planning was reported as a priority or unmet need across all participant groups [13, 15, 46, 50, 60–63]. Older people (all) identified better coordination of hospital discharge planning as a priority [45, 46]. A shared approach to care and discharge planning needed to include the older person, their carers, relatives, and relevant health and social care professionals (HSCPs) in decision-making processes.

Access to services

Access to services for older people was identified as a priority by and for non-frail older people including improving accessibility of services [12, 16, 18, 20, 29, 42, 44, 48, 64] (e.g. staying local, being able to get appointments, better transport), facilitating better understanding of what is available and how older people might better navigate the system [12, 44].

Table 2. Evidence synthesis.

Domain	Priority area	Studies specific to those living with frailty		Studies not specific to those living with frailty	
		Included older people	Did not include older people	Included older people	Did not include older people
		Priority Unmet need	Priority Unmet need	Priority Unmet need	Priority Unmet need
PREVENTION AND MANAGEMENT					
Prevention, recognition and management of chronic conditions/frailty (general)	Prevention of multiple conditions (including most common clusters of multimorbidity; health education)	13		5, 11, 12, 16	14, 15
	Early care planning and/or early or regular contact to help prevent problems rather than waiting until there is a crisis		44		
	Managing (multiple) chronic conditions and complex needs, including their negative impact on quality of life	17		18, 19, 44	
	Which multimorbidity clusters have the greatest burden and worst impact on prognosis?				15
	Symptom and treatment burden (including minimising risk of multiple treatments)				15
	Improving recognition and management of frailty in older people with multiple conditions	13		20	
	Impact of health or treatment on outcomes (clinical, social, financial)		5		
	Prevention of unnecessary hospital visits	12			
	How can frailty measures be used by older people, HSCPs and carers to inform treatment and care decisions?	6			
	Development or identification of the best assessment tools (including tools to identify frailty, improve clinical decision-making and to support treatment decisions)	6			15, 21
Prevention and management of chronic conditions/frailty (specific)	What is the impact of rehabilitation services in preventing and managing frailty (including slowing progression and/or minimising the impact of frailty)?	6			
	Exercise and physical activity to prevent or manage frailty—including how to motivate older adults to be active, reducing sedentary time	6		5	21, 22
	Better interventions to manage incontinence (self-management and management by carers)			23, 24	26, 27, 28
	Prevention and treatment of oral disease, including management approaches as dependency increases			29	
	Managing sensory loss. Contribution of sensory loss to morbidity. Improved support for those with sensory impairment	17		30, 31	26, 27, 28, 32, 14, 33, 34, 35
	What is the impact of diet and nutrition in preventing and managing frailty (including slowing progression and/or minimising the impact of frailty)?	6		36	37
	What are effective ways of assessing and ensuring adequate diet and nutrition for older adults living with frailty?	6			
	Early detection and prevention of dementia / cognitive decline (e.g. due to lack of contact/input)			5, 38	
	Assessing and managing pain (its prevalence, causes, and its impact on daily life)			5	37, 40
					39

(continued)

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Table 2. Evidence synthesis.

Domain	Priority area	Studies specific to those living with frailty		Studies not specific to those living with frailty	
		Included older people	Did not include older people	Included older people	Did not include older people
Improving medication management	Improving medication management for older adults (post-acute care, dispensing aids, alternative formulations, clearer information about medication itself and possible side effects, support for carers, engagement with HSCFs)	Priority 5, 18, 30	Unmet need 42	Priority 5, 18, 30	Unmet need 41
	Stopping medications that may not be needed (concerns about polypharmacy, acceptable and effective de-prescribing interventions)	5	26	43	
IMPROVING HEALTH AND CARE SERVICE PROVISION					
Changes to the health and care system to meet the needs of older people	Tailoring health and care services to older people (e.g. adapting to older people's needs, tailored length of hospital stay, alternative approaches to organising primary care, increased consultation time to discuss complex concerns, managing trauma injuries)	45	11, 12, 18, 44	46	43, 47
	How can care, services and treatment be tailored to meet the needs of older adults living with frailty who are isolated or without family/caregiver support?	6			48
Better integration of health and care services	Better integration of health and care services: How can the health and social care system be better organised to provide integrated care that would better meet the needs of older people with frailty/multiple conditions? Lack of holistic or joined up care. Poor communication between sectors	6	5, 11, 44, 49	33, 40, 42, 46, 51	15, 50, 47, 48
	Managing transitions between care settings (e.g. between hospital and home)	6	12, 18	37, 40, 52, 53	41, 50, 14, 43, 22, 48, 54, 50
Improving healthcare delivery	Community and home-based services to prevent or manage frailty/multimorbidity—including assessment and intervention (e.g. support with ADL), IADL support (e.g. shopping, prescriptions), support with personal care (e.g. feet, nails)	6			
	Improving healthcare delivery (e.g. more assistance, more referrals, not content with care, lack of appropriate services, lack of continuity of carers)	17	19	33, 40, 52, 55	
How can hospital admission and re-admission rates be reduced for older people with multiple conditions?	How can hospital admission and re-admission rates be reduced for older people with multiple conditions?		5		
	Novel models of care		13		
Which models of service delivery are effective and cost-effective for older people with social care needs and multiple long-term conditions?	Which models of service delivery are effective and cost-effective for older people with social care needs and multiple long-term conditions?		59		
	How can the comprehensive geriatric assessment be optimally delivered in different patient populations experiencing multiple conditions in older age? (a later workshop with older people and carers did not prioritise this)		5		
Improving access to oral health services	Improving access to oral health services		29	34, 37	
	Improving end-of-life care/palliative care needs (e.g. functional impairment, emotional distress, managing long-term condition, pain, care preferences)	6	57, 58	56	
Decision-making/care planning	Shared decision-making (to include patient and carer priorities) to enhance care planning/decisions about care (personalised care planning) and retaining choice/control		60, 61	46, 62, 63	15, 50
	Personalised discharge planning—consultation with older person, carers, relatives; provision of appropriate care and equipment at home	45		46	
Better access to services/navigating the system	Better access to services (including, easier access, staying local when accessing services, better access for rural communities)		12, 18, 29, 44	16, 20, 42, 64	48
	What would help older adults to better navigate services/the system? (including difficulty accessing information about what is available)		12, 44		

(continued)

Table 2. Evidence synthesis.

Domain	Priority area	Studies specific to those living with frailty			Studies not specific to those living with frailty		
		Included older people	Did not include older people	Unmet need	Included older people	Did not include older people	Unmet need
Addressing mental health needs		Priority	Unmet need	Unmet need	Priority	Unmet need	Priority
		17	13		5, 65	26, 27, 32, 33, 35, 37, 66, 67, 68, 69	
	Interventions to improve the psychological, social and emotional well-being of older people (including anxiety and distress caused by loss of identity and self-worth, loss of independence, physical ill health, sensory loss, memory loss)						
	Support and service needs of people living with mental health problems						50
	Addressing physical and mental health needs together (possibly integrating care between old age medicine and psychiatry)	70			40		
	Interaction between frailty and psychotropic medications	70					
Improving the skills, knowledge, attitudes and communication of health and social care professionals (HSCPs)		6			10	71	
	What frailty-related skills, knowledge and attitudes should HSCPs have, and what are effective ways of improving these?						
	How can geriatric-related knowledge amongst HSCPs be improved and applied when caring for older adults? (including primary care support for those with multiple conditions)				12		
	Lack of understanding amongst clinicians of older people's needs and experiences. Not respecting patient choice. Consider goals and wishes of older adults				11, 12	26	
	Improved communication skills (fostering relationships, clear discussions, better information provision)		61				
	Workforce training to care for older adults —general (e.g. carers providing home support) and specific (e.g. continence care, oral health, sensory impairment, dementia)				5, 23, 29, 30, 49	16	
Information provision					10, 11, 18, 23, 24, 29	16, 20, 33, 35, 37, 40, 42, 52, 63	21
	Improved provision of and access to health-related information —about symptoms, physical and mental health conditions, available services and support, and treatment options (including self-management—e.g. incontinence, oral health, sedentary time)						
	More accessible information —health literacy can limit engagement with services; information for those with visual impairment				31, 44	72	
IMPROVING DAILY LIFE							
Maintaining independence	How can independent living at home be enabled/maintained for older people? (including self-management)	6, 45	17, 60	13, 59	5, 12, 38	32, 35, 40	14
	How can the barriers to independence be addressed? (e.g. lack of professional support, lack of timely access to equipment, lack of environmental adaptations)				11	53, 73, 74	
	Improved mobility —including aids to improve mobility, prevention of falls, addressing difficulty with daily tasks		17			26, 27, 28, 35, 40, 69	
Environmental adaptations to improve well-being	Adapting the home environment to meet older people's needs (accessibility, mobility aids, aids to support ADL, including design features to support people with dementia)				19, 38	32, 40, 53, 62	
	Creating age-friendly environments —transport, promoting intergenerational integration, adapting environments to older people's needs (e.g. sensory impairment)	6			30, 31, 49, 75		
	Connecting communities —investment in physical, social and digital infrastructure						3
	Transport needs of older adults , including transport as a barrier to service use, and for those with vision loss				31	20, 42, 52, 64	50

(continued)

Table 2. Evidence synthesis.

Domain	Priority area	Studies specific to those living with frailty		Studies not specific to those living with frailty	
		Included older people	Did not include older people	Included older people	Did not include older people
		Priority	Unmet need	Priority	Unmet need
Managing risk and fear of falling	<p>What are effective ways of assessing and reducing risk of falls? (including exercises to reduce falls)</p> <p>How do older people perceive and manage their risk of falls?</p> <p>How can fear of falling be addressed? (including fear of falling when alone)</p>	6	5		
Improving sleep	<p>What is the cause and impact of poor sleep in older people with multiple conditions? What are the most effective ways to address it?</p>	5	5		
Addressing social isolation and loneliness	<p>Social isolation and loneliness—reduction of, increased awareness of, impact on physical and mental health</p> <p>Loneliness, isolation, sadness (due to grief and loss, mobility issues, sexuality, illness, impairment—e.g. sensory loss, dementia)</p> <p>Social activities, connections, contacts, support</p>	5, 11, 18, 44, 49, 76	79	25, 40, 53, 56, 62, 68, 76	14, 48
Addressing inequalities and discrimination	<p>Difficulties with/use of technology to support health/daily living</p> <p>Negative perceptions of older people by society—including loss of value of older adults, stigma of ageing, elder abuse/neglect</p> <p>Addressing other stigma or discrimination (culture, sexuality, dementia, poorer communities, rural communities underserved, health disparities)</p> <p>Cultural and language barriers to accessing services and information</p>	18, 31	40	16, 42, 64, 68, 73, 76, 78, 80	3, 22
INFORMAL CARERS' NEEDS					
Meeting informal carers' needs	<p>What are effective ways of supporting family/caregivers of older adults living with frailty to maintain their own health and well-being and/or that of older adults living with frailty?</p> <p>Family and caregiver roles and dynamics</p> <p>Burden of care (including loss of social contact)</p> <p>Support for carers (services to address carer isolation, burnout, stress; better opportunities for respite, training, understanding needs)</p>	6	13	11	55
PLANNING AHEAD					
Housing needs	<p>What would help older people and their families recognise when living at home is no longer viable? (optimal time for transfer of care)</p> <p>Identifying more living options, and living preferences (e.g. remain in own home, move to care home), including barriers to living independently</p> <p>What are the costs and benefits of alternative housing models, including multigenerational or shared living?</p>	6	81	5, 12, 18, 19, 29, 44	22
Finances	<p>Financial burden of care/worry about the costs of treatment/care—including lack of understanding of care costs, and finances limiting service contact</p>			11, 19, 44, 75	20, 52, 26, 72

N = reference number of report including each priority/unmet need. Density of shading represents the frequency with which a priority was identified.

Mental health needs

The need for interventions to improve the psychological, social and emotional well-being of older people was identified by all groups (although the majority of studies were not specific to those living with frailty). Reports [5, 13, 17, 25, 27, 32, 33, 35, 37, 50, 65–69] suggested that interventions or approaches are needed to support older people with needs arising as a result of ageing—for example, low mood due to physical ill health; or anxiety and distress due to a loss of identity, self-worth or independence. Addressing physical and mental health needs together and exploring the interaction between frailty and psychotropic medications [70] were also identified as priorities for older people living with frailty.

Improving the skills, knowledge and attitudes of health and care professionals

A priority for all older people was the identification of relevant skills, knowledge and attitudes that HSCPs could improve to better support them [6, 10, 71]. This included improved communication, in the form of relationship-building and clarity of information provision [31, 40, 42, 51, 61, 63].

Those not living with frailty also recommended that HSCPs improve their knowledge and understanding of older people's needs and experiences, and expressed a requirement for their wishes and goals to be considered in health and care discussions [11, 12, 26]. There was suggestion that workforce training was needed [5, 16, 23, 29, 30, 49]—including general approaches to working with older people, as well as specific training in areas such as continence care or managing visual or hearing impairment.

Information provision

Those without frailty expressed a need for improved provision of and access to 'easy-to-read' health-related information about conditions, symptoms, available support and treatment including self-management of areas of health such as oral care, and appropriate levels of physical activity [10, 11, 16, 18, 20, 21, 23, 24, 29, 33, 35, 37, 40, 42, 52, 63]. The need for more accessible information, which takes into account levels of health literacy and alternative formats (e.g. to accommodate those with visual impairment), was also identified [31, 44, 72].

Improving daily life

Maintaining independence

Maintaining independent living at home was reported as a priority across all participant groups [5, 6, 12–14, 17, 32, 35, 38, 40, 45, 59, 60]. Some studies reported this to be the most important area for older people [12, 32, 60]. A further priority was the use of aids and equipment to facilitate mobility and safety [17, 26–28, 35, 40, 69], thereby improving independence in activities of daily living whilst minimising the risk of falls.

For those without frailty, addressing the barriers to independence was important [11, 53, 73, 74]—such as improving access to professional support, improving access to equipment and the need for environmental adaptations.

Environmental adaptations to improve well-being

Creating age-friendly environments [6, 30, 31, 49, 75]—for example, intergenerational integration, improved transport systems, and adaptations for those with visual and hearing impairment—was a priority for all older people.

For those without frailty, adaptations to the home environment—for example, improving accessibility and supporting activities of daily living—were identified as ways to improve independence and meet older people's daily needs [19, 32, 38, 40, 53, 62]. The need for better infrastructure to improve community connections [4], and improved transport [20, 22, 31, 42, 50, 52, 64] was also identified by and for older people more generally.

Managing the risk and fear of falling

Assessing and reducing risk of falls (including exercise as a reduction strategy) was a priority expressed by older people [5, 6]. This was expanded upon by those without frailty, to include perception and management of risk [5, 27, 33], and ways in which to address a fear of falling [5, 32].

Improving sleep

One study [5] including older people (not explicitly defined as frail) identified poor sleep as a concern, and suggested investigation of the causes and impact of poor sleep and management strategies.

Addressing social isolation and loneliness

There was a general expressed need for support to manage loneliness, isolation and sadness [26, 38, 40, 53, 56, 58, 60–62, 68, 76]—due to personal circumstances, loss of loved ones, illness, mobility issues or impairments (e.g. visual or hearing loss) that prevented them from leaving the house. Greater social integration and support to address these needs, perhaps through improved provision of and access to social networks and activities, was thought important [14, 17, 28, 32, 37, 44, 48, 55, 56, 60, 67, 68, 77, 78].

Furthermore, those without specified frailty identified the need for reduction of social isolation and loneliness, and greater awareness and consideration of its impact on the physical and mental health of older people [5, 11, 18, 44, 49, 75, 79].

Other factors affecting daily life

Those without frailty reported difficulties experienced in daily life relating to technology [18, 31, 40], ageism [18, 49, 75] and other forms of discrimination [4, 10, 16, 22, 42, 64, 68, 73, 75, 76, 78, 80] linked to culture, sexuality, dementia and locality. Some older people reported cultural

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and language barriers to accessing services and information [20, 52].

Meeting informal carers' needs

Understanding how to support carers' health and well-being was a priority for those living with frailty [6]. Similarly, non-frail groups identified carers' need for support as an area of concern: in particular, the need for services that address carers' isolation, burnout and stress, and improved respite support and training to support them [5, 11, 12, 16, 18, 19, 22, 29, 44, 46, 53, 55].

Planning ahead

Housing needs

Help with the decision about the optimal time to move from home to supported living was a priority for all older people [6, 81]. The need to identify alternative living options—such as multigenerational living, home with support and care home—and to take into account individual living preferences were seen as important areas to consider in the decision-making process [11, 17, 22]. The Canadian frailty PSP [6] included evaluation of the costs and benefits of alternative housing models as one of the top 10 priorities.

Finances

Concerns were expressed about financing care and support, and the need for more information about the costs of care [11, 19, 20, 26, 44, 52, 72, 75].

Discussion

Summary of findings

We reviewed 75 reports of the priorities and unmet needs of older people. The majority ($N = 65$) included older people in their sample, whilst others reported the priorities as expressed by those with personal or professional contact with older people. Priority areas and themes were often inter-related: for example, prevention and management of frailty would improve daily life; and an improvement in the knowledge and skills of health care professionals might lead to more fruitful discussions about care planning. An overarching theme therefore might be the need for 'tailored and collaborative provision of care and support to older people'.

We included the JLA frailty [6] and multiple conditions in later life [5] PSPs in our review: these identified priorities were incorporated into our findings. Some of these priorities were endorsed by other studies. Our evidence synthesis identified additional priority areas relevant to older people with and without frailty, including the tailoring of health care services to older people's needs, improved communication with health and care professionals, shared decision-making about care and personalised discharge planning. A number of

priorities that were not included in the PSPs fell within our themes of 'improving health and care provision' (e.g. better access to services, improved provision of health-related information) and 'improving daily life' (e.g. improved mobility; the need for social activity, support and connection; and ways to address loneliness, isolation and sadness).

Many of our identified priority areas were generated by those without overtly defined frailty; over 20 additional studies' had samples with morbidities that might lead some to be classified as having frailty. These studies elicited priorities that may nevertheless be relevant to those with frailty—implied by agreement across stakeholder groups on a broad number of domains and priority areas.

A recent scoping review [82] has also explored the findings of prior research priority-setting initiatives for older people; however, the researchers did not restrict their search to the community setting, and have identified broad research topics and Population-Intervention-Comparator-Outcome priorities. They focussed on priority setting initiatives, whilst we explored the wider literature to identify priorities and unmet needs; whilst there is overlap between our work, our findings are complementary.

Methodological considerations

Our search was limited to the 12 preceding years (2010 onwards), which might have excluded reports of relevance. However, we recovered a large body of literature from a wide range of countries and consider our findings to be sufficiently representative of older people's priorities.

By including priorities 'and' unmet needs, and by including 'older people' without limiting the search to those of a specific age or level of frailty, we might have been insufficiently targeted in our reporting of research priorities. However, we have clearly indicated which priorities were elicited by different stakeholder groups, so have identified the priorities of both those with frailty as well as the wider cohort of older people. We did not exclude studies that focussed on particular areas such as visual impairment or incontinence. By including these studies, we have inevitably identified priority areas that were selected by researchers rather than generated by participants; however, this does not diminish their importance to older people, and their findings illustrate the challenges that older people face.

Testing of our initial search using 'frailty' terms identified few reports, and during data extraction we found that populations were not always well defined. We would recommend that others searching for frailty-related research adopt similarly 'wide' search criteria to avoid important omissions.

Implications

It is interesting to note that some areas identified as priorities or unmet needs do have an existing evidence base (e.g. falls prevention [83]), suggesting that implementation may need to be addressed. The findings of our review provide a valuable resource for other researchers wishing to focus

their research on areas of importance for older people living with and without frailty. Findings will also be of interest and importance to health and care staff—to inform them of the areas in which older people feel that they lack knowledge or are under-supported. Specifically, our research team [84] have used the review findings to construct a survey for older people to identify their top priorities for future research (to be published). These priorities will inform intervention development and evaluation in areas relevant to older people, selected to also align with national policy initiatives to support older people to live well at home for longer [85].

Conclusion

We have brought together recently published priorities and needs identified by and for older people, including those with frailty. This comprehensive review of the literature provides a concise summary of priorities that will usefully inform the direction of future research internationally.

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