

QUALITATIVE PAPER

What are lay UK public perceptions of frailty: a scoping review

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Abstract

Rationale and objective: Perceptions of frailty can influence how families cope, quality of life and access to support services. Yet little is known of how lay members of the UK general public perceive frailty. This scoping review aimed to explore how frailty is perceived among the lay public in the United Kingdom.

Methods: The established scoping review methodology by Arksey and O'Malley was followed and searches were conducted across eight electronic databases and grey literature websites for articles published between 1990 and August 2022. In total, 6,705 articles were identified, of which six were included in the review. Data were analysed using Braun and Clarke's thematic analysis framework.

Results: Three key themes were identified; frailty as a normal part of ageing, perceived consequences of frailty and coping with frailty. Overall, frailty has negative connotations and is perceived as linked to a natural part of the ageing process, increased dependency, loss of identity and social exclusion and stigma. However, it is unclear whether these perceptions have a direct bearing on access to support services for communities.

Conclusion and implications: This review identifies that it is imperative for health and social care service providers to consider the individual meaning of frailty for older people and families, to understand and integrate their particular needs and preferences when planning and delivering person centred frailty care and support. There is also a need for development of interventions that focus on increasing education and reducing stigma around frailty in order to change frailty perceptions in the UK.

Keywords: frailty, older people, ageing, perspectives, United Kingdom, qualitative research

Key points

- Frailty is a clinical health condition related to a vast range of poor outcomes for older people.
- Perceptions of frailty influence coping strategies, quality of life and decisions to access support services.
- The lay UK public perceive frailty as normal ageing, dependency, identity loss, social exclusion and stigma.
- Individual coping strategies are perceived as valuable for managing frailty.
- Future research is needed on minority ethnic communities' perceptions of frailty to understand their specific support needs.

Introduction

Due to a rapid rise in the older adult population globally, frailty has received increasing attention and is now deemed a worldwide public health concern [1, 2]. Frailty is a long-term health condition clinically defined by phenotypic (visible) characteristics and accumulation of multiple deficits in later

life [3]. It is depicted by a decline across various physiological systems as well as increase in disease, co-morbidity, disability and cognitive, psychological and social decline [2, 4, 5]. Frailty is related to a vast range of unfavourable outcomes for older people, including untimely death [2, 6]. Given the increase in the proportion of people living longer, it is likely that the number of people with frailty will also increase.

The UK population consists of in excess of 66 million people [7] of which 8% are from minority ethnic communities [8]. It is estimated that 44 in every 1,000 older people are living with frailty [9], with around 15% of these being adults aged over 65 living in the community [10]. From among these, older adults of a South Asian heritage, specifically those from Pakistani, Indian and Bangladeshi backgrounds, make up the largest ethnic minority population in the UK, and are particularly predisposed to frailty [11]. Frail older adults possess a variety of intricate health and social care needs and comorbidities, and use a substantial proportion of services [12]. This can incur higher costs and major resource implications for health care systems [13]. These systems are generally ill-equipped to cope with the multifaceted health needs of frail adults [14] and can lead to them receiving inadequate quality of care [15]. This is problematic and can lead to health services being inefficient in meeting the needs of older people, and extensive costs for older people and health care systems alike [16].

Costs of frailty to the National Healthcare System (NHS) are estimated to be in the region of £5.8 billion a year [17]. The National Health Service & Community Care Act introduced in 1990 has sought to compel health care services to use person centred integrated services when supporting older adults to remain in the community and also reduce health care costs. Accordingly, the NHS England Long Term plan (2019) [18] has emphasised the need for early identification of frailty and use of preventative strategies to support people to age well and maintain independence through timely access to GPs and a range of external multidisciplinary professionals for practical and emotional support for frailty [18]. Yet, only 9–10% of frail adults living in the community access primary, community or social care support services for management of frailty [19]. This can impede on the overall improvement of their health and wellbeing outcomes. It may however be possible to reduce frailty costs and improve access to support services for frail adults by understanding how frailty is perceived by older people and their family members. In doing so, services could be designed to ensure families are able to access tailored care which can increase positive health effects for older people, as well as generate cost effectiveness for health care systems [20].

Perceptions of health significantly influence how frailty progresses and the outcomes of the syndrome [21]. How an individual perceives frailty can influence health seeking behaviours, coping strategies, self-efficacy and psychological health [22]. These perceptions also determine how families cope with frailty and its impact on quality of life [21, 23]. There is a growing body of evidence to suggest that perceptions of an illness or condition can influence decisions to take up services and support, with not accessing services having a detrimental impact on health and wellbeing [24].

Globally, increasing evidence around lay people's perceptions of frailty demonstrates the multifaceted views of individuals and family members living with frailty. For example, a qualitative US study [25] found that frail individuals and the wider public challenged medical definitions of frailty which generated an aversion towards accepting the

condition. On the other hand, Pan *et al.* [26] found older adults in New Zealand perceived the term frailty as linked to negative connotations, with individuals often assigning the term to others rather than themselves. An integrated review across 10 countries [27] found older adults viewed frailty as a natural course of ageing which included physical and cognitive limitations, as well as social decline. In addition, Dutch and Australian adults living in the community viewed frailty as a condition associated with both physical and psychological deterioration alongside chronic disease [28, 29]. Together, such differing perceptions have important implications for policy and practice as they have the potential to negatively impact on access to and service engagement for families where a person is living with frailty.

With the growing interest in frailty and differences among views and beliefs about frailty across the world, it was considered timely to review the UK evidence. This is important, as should frailty remain unmanaged for older people, it is likely costs to UK health care systems will grow exponentially as will deteriorating health status and a surge in disablement over time for frail adults [30]. This is also an important topic to improve management of the syndrome and ensure the NHS meets people's needs in the most efficient and effective way. The aim of this scoping review was therefore to explore and map all literature relating to views, beliefs and knowledge of frailty among the lay UK public, to inform frailty support services and also guide policy and practice at a health and social care system service level.

Methods

The Arksey and O'Malley [31] framework with direction from Levac *et al.* [32] was used to conduct the scoping review. A scoping review allows for an all-round overview through mapping of the current knowledge base in the area of frailty perceptions. In particular, the objective of the scoping review was to identify what types of evidence were available in the field, distinguish key characteristics or factors related to perceptions, and identify gaps in the body of literature [33]. All study designs were included as well as sources outside of peer-reviewed academic journals, such as grey literature from charity organisations. This is important as publications on charity websites may offer valuable evidence-based guidance and insight related to services provided for frailty which are relevant to the review question. A five-stage iterative process was followed; identifying the review question, identifying relevant literature, study selection, charting the data and collating, summarising and reporting results. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist was followed for comprehensive, transparent and coherent reporting of the literature [34].

Review question

A broad review question was formulated using the PICO framework to address the aim of this review: 'What are lay public perceptions of frailty within the UK?'

Inclusion and exclusion criteria

Key search terms and inclusion criteria were established through collaborative discussion with co-authors and an expert subject librarian. This ensured an effective search strategy which would appropriately address the review question. Articles were deemed suitable if they included primary or secondary research of any design where the focus related to lay perceptions of frailty, were conducted in community, residential care homes or primary/secondary/acute care settings; encompassed evidence-based guidelines, reports, review articles, expert opinions, theses or dissertations, government documents and conference articles/abstracts, were based within UK settings and published from 1990 (inclusive) onwards due to the implementation of the Community Care Act.

Search strategy

The databases MEDLINE, CINAHL, EMBASE, PsycINFO, AMED, Psychological and Behavioural Sciences, Scopus and Web of Science were searched between March and June 2020 and updated in August 2022. Key search terms were truncated and wildcards used and adjusted in line with the respective requirements of each database to maximise results. Search terms were connected via several combinations using the boolean operators AND or OR as appropriate. Limits (publication dates and English language) were applied to yield a number of records or articles related to frailty perceptions. Final search terms included: ('Frail*' OR 'prefrail*' OR 'sarcop?eni*' OR 'cumulative deficit*') AND ('perception*' OR 'perceive' OR 'perspective*' OR 'knowledge' OR 'understand*' OR 'attitude*' OR 'recognition' OR 'recognise' OR 'aware*' OR 'belief*' OR 'believe' OR 'view*' OR 'opinion*' OR 'experience*' OR 'reflect' OR 'reflection*' OR 'representation*' OR 'cognition*') AND ('UK' OR 'United Kingdom' OR 'Britain' OR 'British' OR 'England' OR 'Wales' OR 'Welsh' OR 'Northern Ireland' OR 'Scotland' OR 'Scottish' OR 'London' OR 'Ireland' OR 'Irish'). Grey literature was sought through reference lists, internet resources, citations within studies and grey literature search engines/organisations. These were Social Care Online, CORE, PROSPERO, The Campbell Collaboration, OpenGrey, The King's Fund, British Geriatrics Society, The Health Foundation, Age UK, Ipsos MORI, Acute Frailty Network, National Voices and East Midlands Academic Health Science Network.

Study selection

All study titles were reviewed independently by the first author and those related to lay public frailty perceptions were selected for further review. Study selection criterion was referred to and applied consistently whilst reviewing title and abstracts, and full texts acquired of studies considered relevant to address the review questions. All full texts were screened twice and any concerns regarding studies that fell amid the study criterion were discussed with co-authors. A

consensus was reached as to the un/suitability of the study in line with inclusion and exclusion criteria. The entirety of the study selection process was documented through its stages on a PRISMA flow chart (Figure 1) to transparently map records identified/included/excluded and provide reasons for those deemed irrelevant [35].

Data extraction and analysis

A data-charting form was created by the first author through Microsoft Word and approved by all co-authors (Appendix 1 available in *Age and Ageing* online). This ensured key variables including author(s), year, study type, aims, methodology, sample, ethnic minority participants in sample and findings would assist in answering the review question [32]. Following pilot of the data-charting form on a small selection of articles and necessary adjustments made, relevant information from individual studies was extracted [31] and discussions held with co-authors to double-check data consistency with the review question. As this was a scoping review, quality assessment of articles was not conducted due to the focus being on existence of relevant frailty literature rather than its quality. Consistent with recommendations by Levac *et al.* [32], Braun and Clarke's [36] thematic analysis framework was utilised to develop key themes and summarise and narratively report findings (Table 1), due to it being deemed exemplary for scoping reviews.

Results

In total, 6,705 records were identified through database searches and 25 additional records via grey literature sources. Following removal of duplicates via Endnote X9, 3,283 records remained, screened by title and abstract. Of these, 3,161 were immediately excluded due to failure to meet the inclusion criteria. Next, 122 full-text articles were assessed for eligibility, of which 116 were further excluded for the following reasons; not being related to lay frailty perceptions ($n = 47$), interventions focused ($n = 12$), services focused ($n = 29$) and based outside the UK ($n = 28$). Final sources of evidence consisted of six articles including three peer-reviewed and three reports from charity organisations (Figure 1).

Study characteristics

Within the review, methodological designs included qualitative ($n = 5$) and mixed methods ($n = 1$) research. Data collection methods were interviews ($n = 3$), a combination of focus groups, online surveys and in-depth interviews ($n = 2$) and a systematic review ($n = 1$). Publication dates were all between 2013 and 2018. Study designs were informed by a grounded theory approach ($n = 2$), a psychosocial narrative approach ($n = 1$) and ethnography ($n = 2$). One remaining article did not explicitly state their chosen methodology. Four articles included both males and females within their study samples, while two did not specify gender. Three studies included

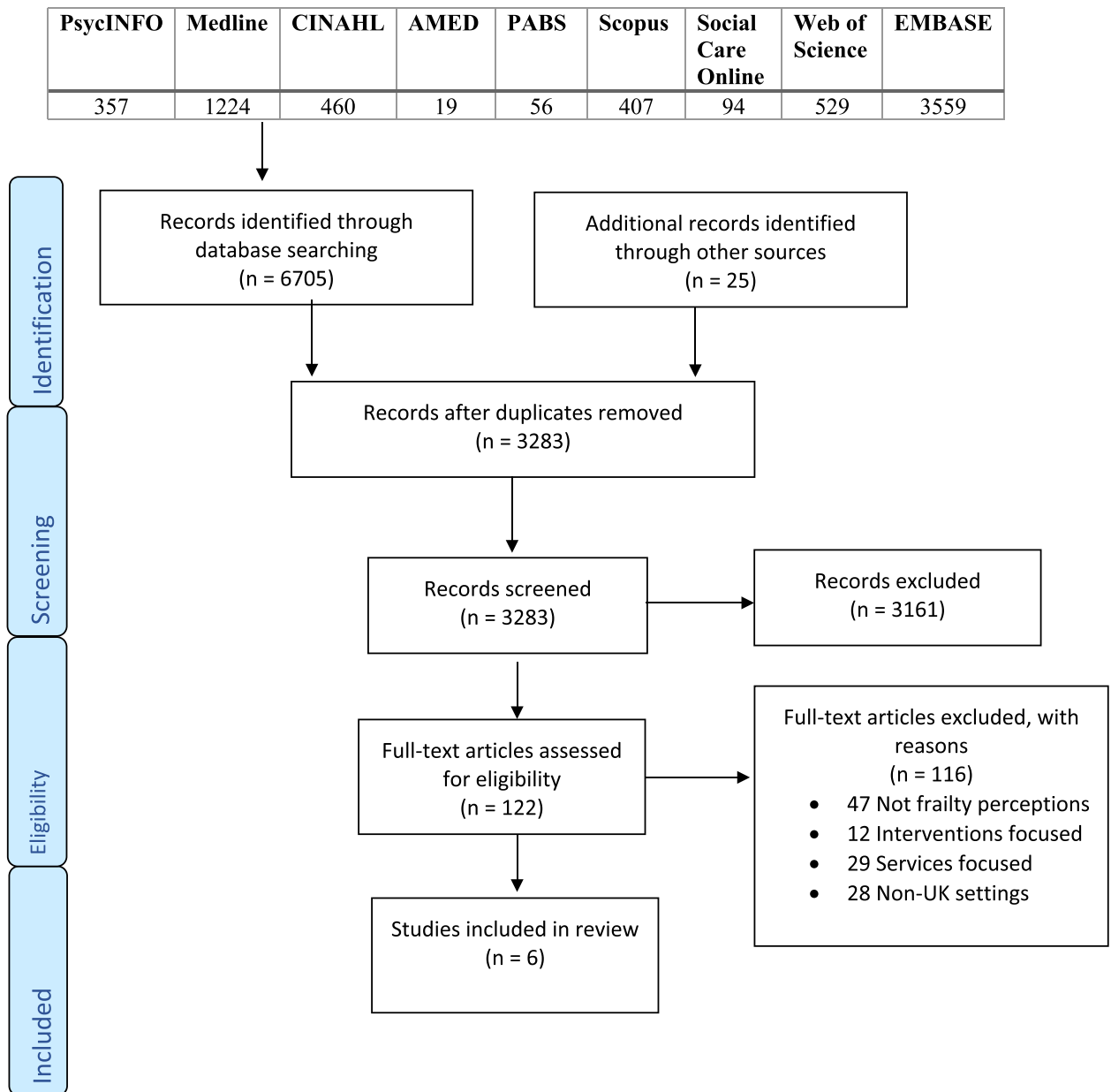


Figure 1. Databases and PRISMA flow diagram

Table 1. Braun and Clarke [36] thematic analysis framework

Familiarisation with data	First author familiarised themselves with the data by reading and rereading data; making notes
Generate initial codes	First author assigned initial codes systematically across entire dataset; extracted data relevant to codes; discussion held of initial codes with co-authors; some codes discarded
Search for themes	All authors assigned final codes and collaborated to search for and generate themes; gathered all data relevant to potential themes
Review themes	All authors collectively reviewed themes relative to coded extracts and dataset to ensure consistency
Define and name themes	Authors collaborated to refine and generate clear definitions of theme names in accordance to the review question
Producing the report	Discussion held with all authors to select and offer final analysis of clear extract examples in relation to review question and literature; first author produced final report

minority ethnic participants comprising of Black, Indian and other ethnicities within their main sample but provided no further clarification on ethnic backgrounds among ‘other’ ethnicities. All studies comprised of lay older adults and

family members/carers with experiences of frailty. The focus across the majority of studies was on research objectives relating to older people’s knowledge, views, beliefs and experiences of frailty ($n = 5$); however, one study extended this

Table 2. Themes

Author(s) and year	Frailty as a normal part of ageing	Perceived consequences of frailty	Coping with frailty
Ipsos MORI (2014) [37]		x	x
Britain Thinks (2015) [38]	X	x	x
National Voices (2014) [40]		x	x
Nicholson <i>et al.</i> (2013) [39]	X	x	x
Warmoth (2015) [41]	X	x	x
Warmoth <i>et al.</i> (2016) [21]	X	x	x
Total	4	6	6

to include general perceptions of the public (Appendix 1 available in *Age and Ageing* online).

Results of synthesis

Three main themes were identified from the evidence drawn within the review. These were frailty as a normal part of ageing, perceived consequences of frailty and coping with frailty. The majority of themes were apparent across all literature and therefore merged for the purpose of narrative reporting (Table 2). Findings were reported in a descriptive format to provide an overview of lay perceptions of frailty in the UK.

Frailty as a normal part of ageing

Across four studies, frailty was perceived to be a normal part of ageing [21, 38, 39, 41]. Within this context, ageing was defined as a natural process which encompassed physical, psychological and social decline as people grew older. One study [39] found frailty was associated with inevitable deterioration which could not be altered or changed. In another study [21], there was a belief that frailty comprised various factors beyond a person’s control when reaching old age. These comprised ill health, disability and chronic diseases [21, 41] and were generally accepted that frailty was unavoidable. While frailty was considered a normal part of ageing, some individuals also reported feelings of vulnerability and uncertainty due to the decline in their physical abilities:

‘feeling “frustrated”, ‘low’ and . . . ‘struggling’ emerged as words that resonated particularly strongly’ [38, p. 17].

Perceived consequences of frailty

All studies reported that frailty was understood to be concomitant with dependency, loss of identity and social exclusion and stigma.

Dependency

Across three articles frailty was perceived to create dependency through reliance on others when management of daily living tasks became difficult [37, 38, 40]. Frailty was also related to dependency if assigned formal carers through

external domiciliary services. This was associated with becoming dependent on outsiders to help with basic tasks, although these views were mainly related to male adults [37, 39, 40]. Findings from Britain Thinks [38] further revealed perceptions of dependency arose from a limited knowledge of frailty and related support available and therefore could be avoided by increasing knowledge. Here, frailty was considered an extreme condition where individuals required support from care homes. Consequently, people did not always seek external support when they may have needed help to maintain their independent living in the community, instead preferring to ‘look for own solutions rather than external sources of support’ [38, p. 19].

There was also a belief that avoiding disclosing day to day difficulties to others would help maintain independence. An example from a case study in a report by Britain Thinks [38] highlighted one participant’s attempts to maintain his independence in spite of the difficulties he experienced as:

‘Akhtar is finding it increasingly difficult to do things for himself, and the furthest he can walk outdoors is now the corner shop at the end of his road . . . but he would never say this to anyone, not even his wife’ [38, p. 21].

However, National Voices [40] found in some cases that frailty was not perceived to define or limit individuals. A case study described a 100-year-old participant’s perceived independence as:

‘. . . he did not identify himself as being frail. He lived alone with only domestic assistance. He used an iPad and went to Pilates classes twice a week. He described his health as ‘pretty good’ [40, p. 15].

Loss of identity

All six papers identified that frailty was perceived to be associated with loss of identity. This was related to accumulation of health deficits and the manner in which individuals were viewed [21]. There was also a general perception that frailty altered an individual’s social identity and place in the world, with a view that it was now ‘. . . a different pace of life’ [39, p. 1176] to what was once known. Another study [39] showed there was a perception that allowing outsiders to provide support for frailty could also lead to loss of identity through fear of being belittled, which led to loss of confidence and personhood [39].

Social exclusion and stigma

Across the studies, most people perceived frailty to be a condition which caused social exclusion and stigma. Here, there was a belief among participants that individuals were treated unfavourably by friends and family members following a frail diagnosis, through negative judgement of frail people’s capabilities [37] and being excluded or avoided from social activities [21, 38, 39].

Frailty was also believed to limit access to society and cause social exclusion due to inadequate structural, transport and community facilities [39]. This caused

individuals to remain indoors, thereby increasing social disconnection. Some people also socially excluded themselves due to embarrassment, believing if they were seen using assistive aids by others they would be considered dependent [21, 38, 39]. Moreover, frailty was related to social exclusion through loss of community interactions and connections with the outside world. This was caused by disengagement, loneliness and isolation when significant others had passed on [37, 41].

All studies also reported that frailty led to people being stigmatised by causing negative stereotypes and discrimination as physical, cognitive and interpersonal decline accumulated in older adults. One study [21] found frail older people were viewed as in need of dire assistance, with age-related stereotypes leading to stigmatisation by others. There was also a general perception that frail individuals would likely experience stigma as they were viewed as physically and mentally impaired, and likened to ‘a skeleton that can’t move’ [37, p. 17].

Moreover, across three studies [21, 38, 41], participants frequently stereotyped frail individuals as mostly female, hunched over, unsteady, slow-paced, grey-haired, fragile and frequently falling over and incurring fractures. This was believed to add to experiences of stigmatisation, with one participant acknowledging the negative impact on frail individuals by stating,

“I wouldn’t . . . want to stigmatise people by saying . . . I think you’re frail you are getting older and you can’t do as much as you perhaps would like to do” [21, p. 493].

The term frail was therefore attributed to others deemed to have poorer health [21, 37, 39–41].

Coping with frailty

Across all six studies, participants believed that frailty could be circumvented or controlled through active coping strategies. For some participants, this included creating and sustaining connections and increasing community interaction, to help preserve their identity and reduce social isolation [39, 40]. Loss of identity was also believed to be avoidable by refusing to self-identify as frail [40, 41]. Here, two studies [21, 38] reported defiance attached with frailty, even for those medically diagnosed with the condition. One participant expressed their rejection of a frail identity as:

‘Do I look frail to you?! I’m not frail. That’s someone who can’t do anything, who’s wasting away. Thin and skinny.’ [38, p. 11].

Some individuals perceived coping strategies included increasing their own self-worth through ‘doing things for others’ [40, p. 15], keeping physically active and maintaining religious faith [37]. Ipsos MORI [37] described one African Caribbean participant’s use of religion to maintain emotional wellbeing as:

‘her faith plays a big role in her life. She says that without her belief she would have “gone mad”’ [37, p. 62].

Many participants across all six studies also believed using positive reframing as a coping strategy afforded a means to retain independence and control over their own lives. It was believed that frail individuals were able to do what they desired when they desired, as well as ‘getting out and about’ [40, p. 8]. This was expressed by one participant as:

‘I can go to bed when I want, get up when I want. I can think for myself. I don’t rely on other people, as long as I’ve got my mobility’ [40, p. 5].

Some respondents perceived accepting support from family, friends and caregivers as a useful coping strategy. They believed that by receiving assistance, individuals with frailty were better able to adapt to fluctuating health needs and, in turn, enjoy a higher quality of life [37, 38].

Discussion

This scoping review aimed to explore the views, beliefs and knowledge of frailty among the lay UK public. A total of six studies were identified with findings suggesting that frailty was considered a normal part of the ageing process but led to increased dependency, loss of identity and social exclusion and stigma. However, frailty was also perceived as able to be controlled by use of individual coping strategies.

Findings of the review demonstrate that consistent with previous worldwide literature [25, 27–29, 42, 43], members of the lay UK public view frailty as an inevitable, natural part of growing older. It is also linked to a number of chronic diseases and disabilities which are expected to accumulate over time, and loss of psychological, physical and cognitive abilities are believed to be inevitable. The UK public also believe that frailty has the potential to limit independence, leading to social isolation and loneliness for older people. This suggests that older adults and family members may have misconceptions related to frailty. Perceptions of frailty may overlap with perceptions of ageing whereby negative beliefs about ageing influence perceived expectations, levels of control and emotional responses to getting older among individuals [44]. Such poor awareness of frailty may potentially impede on decisions to access services which are vital to self-management of health conditions and living well in older age [45]. There also appears to be a presumption that utilising health services would be of no point as natural deterioration cannot be reversed. Gaining insight into older people’s views on ageing and preferred coping strategies through discussion between primary health care providers and older people can therefore be of utmost importance when attempting to tailor appropriate care for older people and their family members [46]. This can aid in dispelling the myth that frailty is a normal part of ageing, and improve likelihood of services being accessed if individuals believe frailty is distinct to ageing, and can be controlled.

The UK public also believe frailty can lead to imposition of negative stereotypes by others, causing unwanted experiences of discrimination for older people. These findings resonate with those of the USA and New Zealand [25, 26]

whereby the term frail is associated with negative inferences and the label of being frail is actively rejected as applicable to oneself. There could therefore also be a reluctance to accept the condition among some members of the wider UK public, and a preference to attribute the term to others rather than themselves. Such harmful stereotypes can cause older individuals to withdraw from society and perhaps also cause reluctance in seeking appropriate sources of frailty support. To address this, it is suggested, increasing awareness of frailty through education may aid in removing stigma attached to the condition and improve attitudes and care towards older adults living with frailty.

For some members of the wider UK public, remaining physically active, maintaining faith and retaining social connections are seen to have a positive effect on health and wellbeing, which also enables them to remain an integral part of society. These findings are similar to those of Parish *et al.* [27] in that if older people perceive frailty as manageable, they may engage in health and social behaviours which prolong their longevity and overall wellbeing [27]. It is therefore important for frailty services to work collaboratively with community and voluntary organisations to ascertain what particular health and social areas of life are important for older people and their family members, and how with whole families' input, these can be incorporated into holistic integrated care plans. In doing so, older people and their family members may consider support services as their first point of call to retain older people's full potential in living independently with changing health needs, and continuing social engagement within their known community environments. It is thus possible that families wherein a person is living with frailty may feel comfortable in the knowledge that support and care have been carefully shaped and aligned to their loved ones' most important needs, preferences and values.

However, a number of gaps were identified from the literature. Firstly, all studies included samples most often recruited through services, which runs the risk of limited and biased samples; representing only those within services and not people outside of organisations. Also, from six small-scale studies, only two studies [37, 38] carried out recruitment across more than one location of the UK, deeming the findings to be of limited generalisability to the wider population. Further, while all studies included a qualitative methodology design that is useful for capturing rich meanings of participants' constructs of frailty, encompassing the use of a phenomenological approach may also have been helpful for understanding perspectives and lived experiences of frailty. Moreover, all but one article [41] included the socioeconomic status of participants, making it difficult to ascertain how participants' perceptions are influenced by income, education and occupation. Finally, it was particularly noted that there appeared to be a lack of diversity among the study samples of the six articles included in this review. Three academic journals did not include or failed to mention members of any ethnic minority groups as participants within their samples. Of the three studies that

did, one [40] provided no direct breakdown and placed no emphasis on minority ethnic perceptions in their findings despite Indians, Blacks and others making up 32 participants in their sample demographics of 157 people. Given that from among people from ethnic minority backgrounds, the South Asian population is the largest and fastest growing minority ethnic group within the UK [47] and particularly disposed to frailty [11] the gaps relating to their perceptions of frailty cannot be ignored. Transferring frailty perceptions across different populations may lead to misinterpretations of the specific needs of UK minority ethnic populations, which may be influenced by cultural or religious beliefs. This could lead to the assumption that one size fits all for frailty support and service provision.

Limitations

Certain limitations to this review are acknowledged. In spite of efforts to include all relevant studies to be as wide ranging as possible, articles published in languages other than English were not considered. This may have excluded potential articles published in other languages relevant to this research. There was also a lack of grey literature found, with only three reports yielded from charity organisations. That said, the aim of the review was to ascertain the coverage of research pertinent to frailty perceptions in the UK. This scoping review identified only six small-scale studies on perceptions of frailty in the UK with very little included on perspectives of minority ethnic populations, specifically South Asian communities.

Conclusion and implications

Understanding perceptions of frailty and how these influence access to support services for older people and their families is important to build and shape frailty support services. It is imperative for health and social care service providers to consider the individual meaning of frailty for older people and their families to understand their particular needs and preferences, and integrate these into care plans when planning and delivering person-centred frailty care and support. There is also a need for development of interventions that focus on improving public education and reducing stigma around frailty in order to change frailty perceptions in the UK. Future research is warranted on how South Asian communities perceive and experience frailty, to inform policy guidance and develop culturally targeted frailty interventions at a health and social care system service level for South Asian families living with frailty in the UK.

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