

## QUALITATIVE PAPER

# Understanding consumer perceptions of frailty screening to inform knowledge translation and health service improvements

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## Abstract

**Background and Objectives:** despite growing support for the clinical application of frailty, including regular frailty screening for older adults, little is known about how older adults perceive frailty screening. The purpose of this study was to examine older adults' perspectives on frailty screening to inform knowledge translation and health service improvements for older adults with frailty.

**Research Design:** interpretive descriptive qualitative design.

**Participants:** a total of 39 non-frail (18%), pre-frail (33%) and frail or very frail (49%) South Australian older adults aged 62–99 years, sampled from community, assisted living and residential aged care settings.

**Methods:** seven focus groups were conducted and analysed by two independent investigators using inductive thematic analysis.

**Results:** three themes were identified. First, older adults question the necessity and logic of an objective frailty measure. Second, older adults believe any efforts at frailty screening need to culminate in an action. Third, older adults emphasise that frailty screening needs to be conducted sensitively given negative perceptions of the term frailty and the potential adverse effects of frailty labelling.

**Discussion and Implications:** previous screening experiences and underlying beliefs about the nature of frailty as inevitable shaped openness to, and acceptance of, frailty screening. Findings correspond with previous research illuminating the lack of public awareness of frailty and the nascent stage of frailty screening implementation. Incorporating consumer perspectives, along with perspectives of other stakeholder groups when considering implementing frailty screening, is likely to impact uptake and optimise suitability—important considerations in person-centred care provision.

**Keywords:** consumer perspectives, healthy ageing, geriatric assessment, knowledge translation, qualitative research

## Key Points

- Frailty is considered a key pressing challenge accompanying population ageing, catalysing interest in frailty screening.
- Little is known about how older adults perceive frailty screening, which has important implications for person-centred care.
- Older adults in our sample regard frailty screening with scepticism and identify a number of conditions for acceptable screening.

## Consumer Perceptions of Frailty Screening

Frailty has been identified as one of the most pressing and complex challenges accompanying population ageing [1,2]. Frailty is defined as a clinically recognisable state of increased vulnerability to stressors, predisposing individuals to a range of adverse outcomes including falls, disability, increased healthcare utilisation, institutionalisation and mortality [1]. Frailty prevalence estimates vary, with epidemiological studies reporting an international prevalence range of 4.9–27.4% for frailty in adults age 65 years and older and 34.6–50.9% for pre-frailty (i.e. individuals at high risk of progressing to frailty) depending on the region and measurement tool used [3,4].

Screening can detect frailty at individual and societal levels and can inform the implementation of preventative measures and interventions designed to reverse frailty and enhance wellbeing [5]. Although growing evidence supports the benefit of early frailty identification using validated measures [6], frailty screening can be problematized in reference to the availability of resources intended to improve frailty status; extent of provider uptake of frailty screening tools in clinical practice; associated costs, and the perceptions and acceptability of frailty screening for older adults. However, the literature on older persons' views of frailty screening is decidedly limited. This is problematic since extant qualitative research illustrates that older adults often perceive frailty negatively, frequently regarding it as a stigmatising label denoting an irreversible state of impairment and dependency at the end of life [7–9]. Negative perceptions of frailty have been shown to impact on health behaviours in unfavourable ways, for instance, through avoidance behaviours [8–10]. Negative perceptions of frailty can therefore contribute to missed opportunities to detect frailty early and intervene appropriately, to presumably prevent or minimise loss of independence and quality of life. Critically, the increasing interest and movement towards frailty screening risks overlooking the perspective of older adults, who may or may not perceive screening as desirable or appropriate. Should frailty screening move towards implementation, it is imperative that screening approaches are acceptable to older adults [11]. In this study, we attend to this gap by exploring the attitudes of older adults towards frailty screening. To our knowledge, this is one of the largest qualitative studies on the topic and the first to include empirically derived subgroups of older adults (non-frail, pre-frail and frail) living in the community and in residential aged care. This study advances current knowledge by exploring older adults' views on frailty screening, focusing on the clinical implications of these perspectives to inform global efforts at frailty screening, which may overlook the consumer perspective.

## Design and Methods

Detailed information about study methods is available in the study protocol [7]. We conducted an interpretive descriptive qualitative study [12] with inductive analysis, focusing on

the clinical applications of qualitative data and underpinned by the collaborative knowledge translation framework [13]. We were guided by maximum variation purposive sampling inclusive of the criterion of older age and frailty status to recruit participants from three purposively selected community and residential aged care settings. Sites included two different aged care providers and a university for adults aged over 50 years, in metropolitan South Australia (population 1.3 million). An aged-care recreation coordinator and community-site administrators assisted in identifying suitable participants, drawing from knowledge of participants' degrees of impairment (e.g. cognitive, physical), impacting ability to provide informed consent. Physical and cognitive comorbidities were not assessed. Participants lacking the capacity to provide informed consent for any reason were excluded. Ethical approval was obtained from University of Adelaide Human Research Ethics committee. Participants provided written consent before data collection.

Two research team members collected data between February and April 2017. Participants' objective and self-perceived frailty status were assessed during demographic data collection through self-identification (participants were asked directly whether they identified as 'frail') and the use of the FRAIL questionnaire-screening tool [2]. Data were used for the purpose of analysis and were not tabulated before the interviews or communicated to study participants. Rather than provide frailty scores in the non-medical care context of a focus group with the inability to mobilise referrals and resources as required, participants were encouraged to speak to a healthcare provider about frailty and frailty screening. The frailty status of participants in residential aged care was assessed using the FRAIL-NH scale [14]. Frailty was not defined for participants in advance of the study, since a component of the larger program of work involving this stage of data collection involved assessing baseline understandings and perceptions of frailty [7].

Thirty-nine older adults ( $n = 22$  community-based,  $n = 17$  residential aged care) aged between 62 and 99 years ( $M = 80.6$ ;  $SD = 9.6$ ) participated in seven focus groups ranging in length from 69.51 to 93.32 min ( $M = 81.69$  min). The sample comprised 7 (18%) non-frail, 13 (33%) pre-frail and 19 (49%) frail participants. A demographic summary of participants is presented in Table 1.

Data were audio-recorded, professionally transcribed and managed using Microsoft Excel and NVivo software (version 11.2.2). Two investigators independently and thematically analysed the data through inductive coding and cross-verification of theoretically derived codes. We repeatedly read the transcripts to gain familiarity with the data, generated initial codes while noting preliminary impressions and constructed a flexible coding framework to identify recurrent data patterns. Each focus group was treated as the unit of analysis; we attended to the source of each code at the individual and focus group levels and noted relevant interactional features (e.g. agreement, dispute). Codes were collated into overarching categories and sub-categories and were used as a basis for identifying candidate

**Table 1.** Demographic summary (N = 39)

Focus group	Site	Age range (mean)	Gender (% female)	Non-frail (%)	Pre-frail (%)	Frail (%)
1 (n = 7)	Community/assistive	62–88 (75.1)	57.1	29	57	14
2 (n = 5)	Community/assistive	66–77 (71.4)	80	40	20	20
3 (n = 5)	Community	70–73 (71.8)	100	0	100	0
4 (n = 6)	Residential	87–99 (91.3)	83.3	0	0	100
5 (n = 4)	Residential	81–94 (88.5)	75	0	0	100
6 (n = 7)	Residential	77–98 (91.6)	57.1	0	0	100
7 (n = 5)	Community	68–76 (72.2)	80	60	40	0

themes. Three analysts reviewed and iteratively refined the candidate themes by cross-checking against supportive data. Analytic rigour was promoted through regular co-author consultation wherein interpretations of the data were cross-examined; negative cases (i.e. cases where responses differed significantly from the main body of evidence) across subgroups were interrogated to help postulate explanatory understandings, and representative quotations were selected for inclusion in the reported findings. Data collection and analysis continued until informational redundancy (i.e. theoretical saturation) was achieved.

## Results

Although participants in the community were open to discussing frailty screening, the concept was generally met with scepticism, particularly in relation to (i) the necessity and logic of an objective measure, (ii) whether screening would result in action and (iii) the need for a sensitive approach to overcome negative perceptions and associations of frailty. Frail and very-frail older adults in residential aged care were not particularly amenable to discussing frailty screening and generally viewed frailty as an inevitable part of ageing, often synonymous with disability [15]. Given this, our ability to compare with a high extent of granularity the perspectives on frailty screening between community-based and residential-aged care subgroups was limited. However, the deference from frailty screening was in itself an important finding, differentiating community-based participants most often of robust health from residential aged-care participants who more commonly were of frail or very frail status.

### Theme 1: older adults question the necessity and logic of an objective measure

Participants who discussed frailty screening often expressed that an objective measure was unnecessary because they believed frailty could be identified subjectively, namely by looking at a person and noticing either distinct characteristics (e.g. thinness, hunched back, slow walking speed) or noting a person's inability to perform tasks of daily living independently (e.g. no longer able to feed or dress oneself; requiring an assistive device to move around). Frailty was often seen as something that occurred with advanced age; many participants believed frailty was an inevitable and

unmodifiable component of ageing. Frailty screening was a new concept, and no participant recalled having undergone an objective frailty assessment. The lack of exposure to frailty as a clinically recognisable syndrome rather than a visually identifiable sign of advanced age contributed to the scepticism of the utility of an objective frailty measure [15]. This was exemplified by one community-dwelling participant who stated, 'I think people would know without having to do a survey whether they were frail or not' (FG3, female).

For some, the individualised nature of frailty was seen to render a frailty-screening tool illogical (FG1, FG4, FG5). Frailty screening had not been previously encountered by participants, which supported this sentiment. As one participant expressed, 'You don't go to the doctor and he says you're frail, writes it on a prescription form and says that's the diagnoses. It varies with every individual and some are frail in some areas and not in others' (FG4, male). Whether frailty was objectively measurable at all was also questioned, reflecting queries about the logic of frailty screening. As one community-based female stated, 'how would you measure it, that's the question?' (FG2, male). This was met with agreement among focus group participants.

The logic of a frailty screening tool was also questioned on the basis that older persons' perceptions and interpretations of the questions might differ (e.g. FG 3), and they also might not provide honest answers to questions. As one participant said, 'am I frail? Will you test me? There's no way you're going to go in and say that and if you answer all their questions right which you know as well as anybody, they can answer questions really good. Go out the door and say something stupid but they can... the GP is not going to pick it up' (FG2, female). Participants regarded frailty screening as something a person is unlikely to want to know the answer to. This was regarded as a reason why self-administered screening tools would have low uptake. Thus, while individuals may be able to subjectively identify 'advanced' frailty through self-assessment or observation of others, there was a concurrent sentiment of denial.

### Theme 2: frailty screening needs to result in an action

The necessity and logic of a frailty-screening tool corresponded with how the results of the screening were to be handled. Frailty screening was generally viewed positively if it were to bring results that inform future management.

As one community-based participant expressed, ‘if you can show to the people the relevance of what you’re doing and where it might lead then they’re more likely to be involved’ (FG2, male). Although no participant had undergone frailty screening, many shared negative and burdensome experiences of receiving tests and procedures without then learning the results.

The desire to have the results of frailty screening inform specific action was often linked to other tests. As a female participant in residential care expressed, ‘I suppose it’s the bit the same as when you have your bone density done and if that’s gone right down, what do you do about that? More exercise, more calcium and things like that’ (FG4). Another participant saw the opportunity to link a baseline assessment to subsequent assessments: ‘so down the track if I was to have one now . . . they say no you’re slightly frail but you’ll be doing fine and then five years down the track or six months down the track, whatever it is . . . you have to have somebody comparing it’ (FG1). This concept of continuity was also reflected when participants discussed linking frailty screening into extant management approaches, such as care plans, in order to promote smooth service transitions. Although frequently raised, there was not uniform agreement between participants on this concept.

Although participants wanted frailty screening to inform specific actions, they were wary that sufficient resources were available to provide these services. As one community-based participant expressed, ‘we need someone to take up on the people that are frail and is there the resources available to fix it. I doubt that’ (FG3, female). A component of this discussion related to whether or not frailty was a governmental priority, recognising that implementing frailty screening and ensuring appropriate resources are in place is ‘going to need a massive injection of government funds’ (FG2, male).

### **Theme 3: frailty screening needs to be conducted sensitively**

Participants emphasised that frailty-screening tools need to be presented in a sensitive manner, considering that the term frailty can be perceived negatively, can be fear provoking and could be internalised as a potentially stigmatising label. Participants were concerned that frailty screening, if presented incorrectly, could be detrimental to the older person and prevent positive health behaviours. As one participant expressed, ‘if the person knows that they’re five out of ten, does that then say to them okay, well you know I don’t have to try. You know I’m on my way out sort of thing . . . that’s more of a deterrent’ (F1, female). Conversely, given proper approaches to communicating, some regarded screening as potentially useful, particularly if it provided insight into what could happen in the future. As one community-dwelling male expressed, ‘if the tool could diagnose what’s going to happen to me, then I’d be better placed to go forward’ (FG2).

Participants regarded frailty with fear and apprehension [12], a sentiment that carried forward to frailty screening.

Many participants questioned whether people would actually want to know whether or not they are frail. At times, screening was seen as a means of surveillance (FG3, female) and as reductionistic, where a person is ‘just a statistic, not a person’ (FG3, female). There was agreement between various community-based participants that ‘many people live with their head in the sand’ (FG2, male) and that a frailty diagnosis ‘might tip them over the edge’ (FG2, female), hence underscoring the need for a sensitive approach to screening and corresponding terminology and communication.

Who would administer a frailty-screening tool; how and where it would be administered; and the length, terminology and structure of the tool itself were regarded as important to sensitive screening. Shorter tools were preferred to avoid giving up, or ‘feeling agitated and upset and nervous’ (FG2, female) (e.g. with an hour-long test). Participants open to frailty screening believed the tool needed to be non-threatening to avoid upsetting or causing distress to individuals (FG2, male). The concept of being non-threatening extended past the tool itself to considerations of who would administer the tool and how. For some this meant having a nurse rather than a doctor administer the tool. As one participant stated, ‘Even if you run through a list of questions with a nurse it’s going to be a lot less confronting than doing it with a doctor isn’t it?’ (FG2, female). Considerations related to the limited amount of time one has with a doctor also influenced the discussion, but the notion of ‘de-doctoring’ (FG2, male) frailty screening ‘so that it’s seen as one person to another’ was seen as important to making the process of ageing or frailty seem less foreboding (FG2, male).

## **Discussion and Implications**

Older adults in our sample were generally sceptical about frailty screening. Critically, scepticism about the need for screening was couched in a viewpoint that frailty is detectable through subjective means, which consequently eliminates the need for formal instruments. The perception that frailty is subjectively identifiable accords with previous research on consumer perceptions of frailty and has also been expressed by other key stakeholder groups, including general practitioners [16–18]. Although a limited number of studies have suggested that clinicians can identify frailty subjectively to some extent [19,20], most such studies are characterised by design factors that limit generalisability of results and are dependent on how frailty is defined. To our knowledge, no such evaluation has been undertaken with consumers. While identifying frailty before the point of observable functional decline may be the most appropriate point of identification and early intervention [21], our study suggests older adults are unlikely to accept frailty screening within the limitations of the current health system (e.g. inconsistent communications, concern regarding labelling, lack of supportive resources)—a critical implication given growing interest in frailty screening implementation in primary care. However, given that the nature of qualitative research is inherently situated in specific contexts, time points, personal and social

histories, considerations of the context of the current study and attributes of the participant sample are imperative to the transferability of findings to different populations and contexts.

Participants' potential openness to frailty screening was conditional on numerous factors shaped in part by previous experiences of screening within general practice. Participants' stipulation that screening should be followed by appropriate action reflects long-held principles of ethical screening [22], yet shortcomings in timely communication of results and follow-up is a relatively common source of frustration among patients in general practice [23]. Participant comments regarding a potential lack of resources to support intervention are reflective of a general under-investment in resources allocated for primary and secondary prevention across research and care provision sectors [24]. Further, participants' perspectives that frailty screening should be conducted sensitively accords with a broader body of research relating to the potentially negative impacts of a frailty label for older people, including personal inadequacy linked to shame and distress [25]. Clinicians could help address such perceptions within patient-provider communications, through reframing of the topic from the personal (e.g. personal inadequacy) towards the clinical and emphasising frailty as a dynamic state [26].

Complexities are noted in our findings. For instance, (i) perceptions of frailty as inevitable and observable undermine the perceived utility of an objective frailty screening tool and (ii) these negative associations with the term frailty reduce consumers' desirability of an objective frailty measure; yet (iii) negative associations with the term frailty may be less avoidable if an objective measure were in place (e.g. a person could not simply choose to avoid frailty self-assessment if screening was initiated by a healthcare provider). Given this, it is imperative that any objective measure to identify frailty first requires a shared understanding between healthcare providers and clients that (i) frailty can be present before noting any changes in functional, physical or cognitive status; (ii) frailty is not an indicator of personal inadequacy but rather a sign of increased susceptibility to negative health outcomes that can be modified with appropriate action and (iii) resisting a frailty identity may help avoid negative sequela associated with internalising a frailty label (e.g. determinant to self-image with negative impact on positive health behaviours) [14]. These reflections are not to be interpreted as staunch support of frailty screening, but rather as a consumer-oriented perspective that could help maximise possible benefits of screening while minimising potential concurrent detriments. Research and implementation efforts around frailty screening should account for the perspectives of consumers and the interplay between consumers' past experiences of screening with perspectives of frailty screening and frailty more broadly.

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