Frailty and Social Care: Over- or Under-Familiar Terms?

Jill Manthorpe∗, Steve Iliffe**, Jess Harris***, Jo Moriarty† and Martin Stevens††

*Social Care Workforce Research Unit, King’s College London
E-mail: jill.manthorpe@kcl.ac.uk

**Research Department of Primary Care and Population Health, University College London, Royal Free Hospital, London
E-mail: s.iliffe@ucl.ac.uk

***Social Care Workforce Research Unit, King’s College London
E-mail: jess.harris@kcl.ac.uk

†Social Care Workforce Research Unit, King’s College London
E-mail: jo.moriarty@kcl.ac.uk

††Social Care Workforce Research Unit, King’s College London
E-mail: martin.stevens@kcl.ac.uk

Definitions of frailty are much debated. The focus of this article is on the representation of frailty; who employs the terms ‘frail’ or ‘frailty’ in social care, about whom and with what meanings? We report secondary analysis of interview data from two waves of a longitudinal study starting in 2008. Study participants were 240 social care managers/practitioners working in four English localities. Social care managers and practitioners did not talk at length about frailty as characterising the increasing needs of care users. The minority who talked about frailty used the term in three ways: describing a physical state not including dementia; describing a stable state, as distinct from those dying; and as a combination of physical and mental disabilities (i.e. dementia). Differences among the participants in this study about the meaning of frailty could have implications for policy makers and for communication with other staff, health professionals, older people and their relatives.

Keywords: Frailty, social care, ageing, health, geriatrics.

Introduction

In policy studies, it may be important to understand representations of a ‘problem’ as not static professional or political definitions, images or impressions, but as forming part of a policy debate. Frailty may be one way in which ‘older people’ are becoming problematised and is the subject of this article. As proponents of approaches seeking to ask ‘What is the Problem Represented to be?’ (summarised by the initials WPR) suggest (Bacchi, 2009; 2012), policy analysts can interrogate such ‘problematisations’ and enquire what are the meanings being relied upon, which voices are heard and how, and what, the consequences may be.

The use of the term frailty as a basis for policymaking is said to promote understanding of economics, environments, services and medical care (Fahey, 2007: 71). Over twenty
years ago, the term frailty was used much more broadly. In 1994, the UK government commissioned a review by Tinker et al. (1994) in which frailty was defined as applicable to ‘people aged 65 and over suffering from a chronic illness or some other condition, physical, or mental, which causes some long-term loss of function’ (p. 3). However, as Tinker and her colleagues noted, some of what they classified as services for frail older people in the UK in fact covered other areas of social policy for all older people, such as financial grant aid for housing repairs.

But while there is increasing interest in frailty in health policy and practice in the United Kingdom (UK) (Manthorpe and Iliffe, 2015), there is less evidence of it being critically examined. This growing interest is evidenced by the increase in practice guidelines and professional frameworks that mention frailty, such as those recently revised by the British Geriatrics Society (BGS) and engagement in them by the major UK voluntary sector age-interest group, Age UK (BGS, 2015).

In contrast, social care researchers, care providers, older people and social care policymakers seem to make use of the term frailty less frequently, despite Kaufman's argument more than two decades ago that frailty is socially constructed in response to cultural discourses about surveillance and individualisation, and articulated in the medical encounter (Kaufman, 1994). From a sociology perspective, Grenier (2007) proposed that ‘The concept of frailty represents and orders the context, organisational practices, social representations and lived experiences of care for older people.’ For some, she suggested, frailty may be viewed as a dual combination of physical and socially constructed realities (Grenier, 2002), or even as a powerful practice in public health and social policy where cultural constructions, the global economic rationale of cost containment and the biomedical focus on ageing all collide (Grenier and Hanley, 2010). Others have argued that frailty is simply being used as a replacement for infirmity (Nicholson et al., 2012) or even to describe very old people for whom ‘care’ rather than active treatment is desirable personally and for reasons of social and economic policy (Gilleard and Higgs, 2011). This perspective fits with the idea of frailty as ‘persistent liminality’, a state of imbalance between active living and clinically recognised dying (Nicholson et al., 2012).

Although inter-professional discussions about frailty could be fruitful sources of a wider understanding (Poltawski et al., 2011), much of the debate about frailty focuses on physical problems, often ignoring psychological and social domains (Gobbens et al., 2010). Clinical circles spend much time defining, measuring and debating frailty and its causes, consequences and characteristics, sometimes using ideas borrowed from complex systems theory (Nowak and Hubbard, 2009). There is sustained attention to untangling disability, frailty and co-morbidity (Fried et al., 2004). Within such a classification, subgroups or related terms such as pre-frail, or early frailty are newly emerging in the hope that it may be possible to identify those at risk of frailty so as to better tune treatment, or to prevent or delay the ‘frail’ state. For example, one definition noted the existence of the ‘pre-frail stage, in which one or two criteria are present, (which) identifies a subset at high risk of progressing to frailty’ (Xue, 2011: 1). Others have debated whether frailty is a phenotype (a set of symptoms and physical signs) (Fried et al., 2001), or a state of incremental deficits (Rockwood et al., 2006). Current categorisations tend towards the slightly circular, with one recent definition declaring ‘Frailty is a medical syndrome with numerous causes, characterised by reduced strength, endurance and physiological function, resulting in increased vulnerability to functional decline, dependence and/or death’ (Fairhall et al., 2015).
This paper explores the use of the term ‘frailty’, specifically to whom it is applied and who employs it in social care in England. This is an under-researched topic, despite policy and commissioning imperatives that promote integration and better communication between health and care practitioners, teams and services as in the Care Act 2014. The aim of this article is to inform policy debates about frailty, by highlighting the current multiple understandings and usages of the term and by questioning assumptions about its shared understandings among the workforce supporting older people. Modifying Bacchi’s (2009) approach to problem representation, we explored who employs the terms ‘frail’ or ‘frailty’ in social care, about whom and with what meanings?

Background

As we have discussed above, there are several definitions of frailty and numerous debates over its measurement, but from our perspectives the term frailty is used operationally in the UK in four main ways.

First, frailty is sometimes generally applied to a distinct group of older people who are ill or disabled. As an early editorial on the subject commented, it is feasible to divide the older population into the ‘fit’ or the ‘frail’ (Woodhouse et al., 1988) and, as a recent report on Extra Care housing (purpose built housing with options to pay for care services) suggested, fit and frail may still be seen as separate categories (Burholt et al., 2011). As Grenier (2002) noted, in some jurisdictions the category frailty conveys eligibility for services. This may be one reason why the term has a long tradition of overlap with other categories such as disability or long-term conditions (as in Tinker et al., 1994). Furthermore, ‘elderly mentally frail’ is still sometimes used as a description of some long-term conditions that may be stigmatising and as a euphemism for dementia (Markle-Reid and Browne, 2003). This variation in use may explain the call in the nursing literature for a new theoretical approach to the concept of frailty in older people to counter notions that it is simply age-related and linked to negative and stereotypical views of ageing (Markle-Reid and Browne, 2003).

Second, from a clinical perspective, frailty can mean being particularly vulnerable to potentially severe (in respect of health or disability) consequences from relatively minor illnesses, such as urinary tract infections, or being at high risk of these. Clegg et al (2013: 752) described it as ‘a state of vulnerability to poor resolution of homoeostasis after a stressor event and is a consequence of cumulative decline in many physiological systems during a lifetime’. Vulnerability in ‘plain English’ may spill over into ‘lay’ terminology and professional usage. An older person with a seemingly minor infection (the stressor event) who has their ‘ups and downs’ (after a lifetime of cumulative decline), becomes rapidly much worse (the poor resolution) and gets so ill that they stay in bed or stop previous activities – even ‘going off their legs’ or not regaining their abilities; they too are described as the frail.

Third, in clinical contexts the term frailty gets applied (by clinicians) to particular physical changes including physical limitations or disabilities that can be measured and documented, such as reduced physical activity, slower walking speed, persistent tiredness, loss of weight and muscle weakness (Fried et al., 2004). Many older people will have observed their loss of grip strength when opening bottles or their family may have noticed that they do not hug them as strongly as they used to do, or they cannot get up easily.
Jill Manthorpe et al.

from their chair to answer the doorbell. These changes are relatively easy to document but sometimes are just seen as a sign of ageing.

Fourth, a further clinical way of defining frailty is to conceptualise it as an accumulation of deficits and disabilities. The more things a person experiences as declining – poor vision, hearing loss, arthritis, heart disease or bronchitis – the more they are likely to be or to be becoming frail. This meaning has frailty as a gradation rather than an all-or-none state. However, as the second meaning indicates, it is the instability of problems and their effects on each other that seem to make for frailty, not just having multiple illnesses, disabilities or long-term conditions.

These four meanings overlap and get used in different ways. Recent documents from the BGS (2014; 2015), which are influential in healthcare debates, capture what clinical specialists are thinking about when defining frailty and their possible roles in leading care and treatment for patients in this state or category (BGS, 2014). At times, the term frailty gets attached to a service, or a team, imputing that anyone being treated or cared for in this setting or service is, by definition, frail (and perhaps those on the outside are not). Sometimes ‘mental frailty’ is included in this category, but this term may simply be used euphemistically (see Markle-Reid and Browne, 2003) for mental illness or cognitive impairment. Occasionally ‘frail’ gets applied system wide – not to residents but to the state of the care sector – underfunded, under pressure, potentially highly profitable, but subject to perverse incentives (The Economist, 2014).

There is consensus in clinical circles that frailty is a state of heightened and disproportionate vulnerability due to multi-system failure, and is distinct from multi-morbidity and disability (Iliffe, 2016) despite substantial overlaps. An individual may be frail with few co-morbidities, and disabled but in a stable state without disproportionate vulnerability. Frailty, however defined, seems to be more common in women and some ethnic minorities (Shamliyan et al., 2013), increases in prevalence with age and is associated with higher death rates (Clegg et al., 2013).

However, up to three quarters of people aged over eighty-five years might not be frail, and frailty is not synonymous with being among the ‘oldest old’ (Clegg et al., 2013). For some, it is a dynamic process that evolves over time, offering opportunities for prevention and improvement, or remediation, or stabilisation (Clegg et al., 2013). The dependency oscillations observed in older people who are deemed frail reflect the often-marked changes in functional ability experienced by older people. Nonetheless, at present, progression of frailty is more common than improvement and the onset of frailty frequently results in a spiral of decline to death.

It is now accepted by many healthcare practitioners that frailty also has psychological and social dimensions because it is associated with worsening well-being, taking into account depression and functional limitations, whilst financial resources, neighbourhood security, a sense of belonging and social cohesion may act as a partial buffer against the psychological effects of frailty (Cramm and Nieboer, 2013). Markle-Reid and Browne (2003) also argued that the concept must take into account the contribution of both individual and environmental factors. Maintaining a stronger sense of psychological well-being in later life may protect against the development of physical frailty (Ostir et al., 2004), although the mechanisms underlying this are unclear. As noted, there appears to be a social gradient in frailty, with educational level, income adequacy and income satisfaction being associated with frailty (Hubbard et al., 2014). Older people who are poor and live in deprived neighbourhoods are those most likely to develop frailty (Lang

https://doi.org/10.1017/S1474746416000427 Published online by Cambridge University Press
Frailty and Social Care et al., 2009). Frailty therefore is not just an individual problem, but a public health and political matter. As an example, those who support and care for older people in social care settings may find that offers of rehousing elicit a positive response; ‘ageing in place’ is not what all older people want to do. It is in this context that this article is set. A context where there is appetite among some professionals for the concept of frailty to describe the populations they work with and where addressing and assessing frailty helps professionals to make claims upon funders and service commissioners that older people require the expensive skills and specialism of experts in frailty, both for current frail populations and also for the wider numbers of people who are in its early stages.

Methods

The findings reported in this article draw from a secondary analysis of a large data set of interviews with social care managers and practitioners as part of the Longitudinal Care Work study funded by the Department of Health. Interviews took place in four contrasting English local authority areas varying in size, geography and urban/rural characteristics. The study aims to increase understanding of the factors that facilitate or constrain recruitment and retention in the social care workforce in England which constitutes between 4–6 per cent of the total UK workforce, standing at an estimated 1.45 million workers (Skills for Care, 2015). Started in 2008, the study consists of a longitudinal panel survey of a sample of social care managers and their workforce and interviews at different time points with social care employees, employers, family carers and care recipients. Full details of the recruitment of sites and participants and the methodology of interviewing are available in Manthorpe and Harris (2014).

A total of 240 interviews with social care practitioners (frontline practitioners including home care workers, day centre staff and care home workers) including 121 managers (home care and care home senior staff with managerial responsibilities, almost all holding Registered Manager status as required by the regulator, the Care Quality Commission) were undertaken at Time 1 (T1) (2009–12) and Time 2 (T2) (2011–14). These semi-structured interviews explored perceptions of their roles, activities and job-related histories, their experiences of changes in the profile of care users and of their employing care providing organisation. In the data reported below, identifying features have been removed from the illustrative quotations of both participants and the research sites. Ethical and research governance permissions were received.

Interviews were audio recorded (with permissions), transcribed and the transcripts entered into NVivo to assist with thematic analysis. This permits specific exploration of subjects that were central to the design of the interview schedules and the study’s aims and objectives. Moreover, as Heaton (2004) has argued, large data sets often lend themselves to further enquiry, to address matters that are arising or to investigate topics that were not originally prioritised for analysis. In light of the policy and practice interest in the subject of frailty, this article reports the results of this secondary content analysis in which the terms frailty and frail were searched for and their usage analysed. Following the examples of usage classified by themes, this article discusses the implications of different meanings of the term frailty for policy makers, service providers and partner organisations.
Findings

Three main usages of the term frailty emerged in this exploratory analysis; these are illustrated and discussed in this section. Overall, frailty and frail were not widely used words, and this may be the most important finding of this analysis. If those working in the social care sector do not employ the word frail, then they may be reliant on other professionals to provide a definition and explanation of the term when applied to individuals or to a particular service or team, or may simply overlook the term and miss what is being imputed. For policy makers any pronouncements about frailty and frail populations may appear potentially confusing if they lack specificity or may be seen as only relevant to certain professions or settings.

Usage 1: Elderly frail – not dementia

Across the sites, some participants used the word frail but excluded people with dementia from this category. In one interview, for example, a care home manager made a clear distinction between the current users of their service (the elderly frail) and people with dementia:

They are all elderly frail. We haven’t as yet got to a point where we’ve been approached to provide a service for somebody with dementia. (T1 2277 E)

Another care home manager referred to ‘physically frail and vulnerable’ as describing the current resident profile (T2 1020001 E). In a further large, purpose built, care home with on-site nursing, the manager consolidated terms used to refer to residents with high levels of need as ‘elderly, frail, high dependency, palliative care patients’ (T1 1021001 E). Here, seventy beds were for this group while another fifty were for ‘elderly people with dementia’. The level of need present among all ‘patients’ in what this manager referred to as a nursing home, was said to require considerable attention to inspection and regulatory requirements.

A further distinction was made by another care home manager (T2 21840) between their home’s ‘elderly frail beds’ from the ‘dementia care beds’. In terms of staffing, the elderly frail beds were on an ‘ordinary nursing floor’ to which staff recruitment was not too difficult. In contrast, she observed ‘the residents with Alzheimer’s’ could be ‘quite intimidating’ and frontline care workers could be frightened when they first started working with this group. This home demarcated not only residents but also staff, some of whom expressed clear wishes to work with the ‘elderly frail’ in contrast to working on the dementia floor.

Usage 2: ‘Just’ frail not more dependent

Another care home manager when interviewed at T1 considered that current residents were far more in need of care than previous resident cohorts. Later at T2, she reported that the previous residents could have been described as ‘frail’ or elderly. The profile of new residents in this home was described as changing to be those needing much more support, such as palliative care – ‘people dying from many conditions, not just cancer’ (T2 1021003 E).
In a different site, a care home manager spoke of her previous workplace, another care home, where residents were receiving ‘complex care’. In contrast, her present care home was not undertaking specialist care, such as caring for residents with tracheotomies, but instead its residents were easier to manage, requiring ‘elderly, frail and dementia care’ (T2 1777004 S). Using the term again, she referred to residents being ‘just generally elderly, frail with dementia’. A care home worker described her former workplace as having residents who were ‘quite frail’ and thereby suitable for the ‘very friendly, sort of homely’ residential home where she used to work (T1 4999003 S).

Usage 3: Frail physically and mentally

There were some instances of the term ‘frail elderly’ being inclusive of mental frailty, with this adding to the complexity of someone’s situation and needs. Most mentions of frailty were made by care home managers, but in one of the few mentions of frailty by a practitioner working in the home care or domiciliary sector (T2 2277002 S) this participant commented on the problems of providing continuity of care worker for someone who might find such changes particularly difficult:

When you have got people with dementia, memory problems, blind, you know, frail and a little bit . . . all of a sudden they have got somebody new coming in when they were expecting you, it's just horrible.

This home care worker thought that such cases of ‘very frail people’ would be increasingly common, emphasising perhaps that ‘just frailty’ as in usage 2 above was not any great change from current client or user profiles. A further participant (T1 3324 E) commented that the extensive needs of such clients necessitated more managerial support for care workers:

If there's someone who is really either very frail or very poorly or very depressed then you can support people (staff) through that process.

A care home manager considered that current residents were older, frailer and more often had dementia than previous cohorts of residents (T2 4067 E), necessitating a different, less taxing, pattern of activities in the home. She observed that current residents were:

The kinds of individuals that many moons ago I would say when I started off in care wouldn't apply for a residential care placement . . . they tended to be more mobile and things. And if you did trips and outings an abundance of your residents would want to go out on them; lately with individuals getting older and frailer they tend to want to stay in more, quite a few of the residents.

She further reported that frontline care workers used to take residents shopping but now the ‘older and frailer’ residents asked them to do this for them. Furthermore, this increase in residents’ disability impacted on staff training needs and increased her administrative work around registration with the national inspectorate because ‘residents are getting older and frailer and mental frailty is coming to the fore now’.

https://doi.org/10.1017/S1474746416000427 Published online by Cambridge University Press
Discussion

Our secondary analysis of interviews with 240 social care staff with diverse roles suggests that the terms frail and frailty have low salience when discussing workforce topics, their own roles and the needs of care users, but that when they are used they have three meanings. These were: (1) describing a physical state not including dementia; (2) describing a stable state, as distinct from those dying from various causes; and (3) as a combination of physical and mental disabilities (i.e., dementia). All three meanings refer to distinguishable groups of people, our first usage (see above).

In relation to the English care policy context, the consequences of the word frailty for the social care sector when it is applied by other professionals are not too different from general good practice (Manthorpe and Iliffe, 2015). However, this present analysis suggests that the term is not just being used in different ways by healthcare professionals but that ‘frail’ older people are being represented in different ways in the care sector, which may have implications for care planning, conversations with professionals, understandings of new professional teams and roles (frailty services; frailty teams), and thinking about the usage of such terms with care users and relatives. The differences of usage and understanding of the term frailty within the frontline of care may be potentially confusing for staff, and for care users and their relatives. One particular contradiction we observed was the use of the term frailty to either include people with dementia (mental frailty), or, in contrast, to exclude people with dementia. This contradiction matches the difference between the accumulative deficit model of frailty – which includes cognitive impairment as a possible deficit - and the syndrome model of frailty – which does not. There is a similar mismatch between an operational use of frailty as an indicator of vulnerability and the stable state inferred by some participants.

The variety of uses of the term ‘frailty’ within this study population is congruent with Grenier and Hanley’s (2010) description of the origin of frailty in a ‘collision’ of social, economic and biomedical constructions, whilst the inclusion of dementia within frailty (by some participants) might support Merkle-Reid and Brown’s (2003) view that frailty is sometimes a euphemism for dementia.

Interestingly, the subject of interventions did not emerge in any of the interviews, such as promoting physical activity for all residents in a care home or day centre which are being mooted by health care thinkers; more an indication that the social care sector was already supporting or ‘holding’ many people who were frail, however defined. This touches on the importance, as Bacchi (2009) suggests, of ‘hearing’ the silences. Indeed, as usage 2 indicated, being frail was so common a state among care users that additional emphatic words (for example, ‘very’) were being used by some participants to accompany the term ‘frail’ to emphasise the scale of the disability and dependency on others said to be typical of current care users. The participants in this study described frailty along a spectrum, not in terms of pre-frailty but rather in its end stage. Perhaps not surprisingly, we found no explicit mentions of a public health or community development approach to frailty in the data. There were no comments, for instance, that a move to a long-term care setting could enhance social cohesion or feeling of security among older people living in deprived neighbourhoods or that public health orientated efforts were needed to improve such general living environments on the basis of their potential to reduce the risks of frailty.

The limitations of this study did not focus on the term ‘frailty’, and further studies are needed to investigate specific understandings and usages of the term.

https://doi.org/10.1017/S1474746416000427 Published online by Cambridge University Press
Secondary analysis of data brings problems in terms of exploring data that have been collected for another primary purpose. Only a minority of those interviewed made reference to the term frailty. However, the analysis revealed ways in which the term was being used in conversation that was near casual and did not require specific thinking around ‘correct’ definitions or inhibit discussion by challenging the participant’s confidence that they should know such terms and their ‘correct’ meanings.

Overall, the use of the word frailty alerts primary and secondary care professionals in health services to the very real risk of rapid change in some older people. This seemed not to be the meaning of frail among those participating in our interviews who were from the social care sector. Further research is needed to investigate how medical terms such as frailty impact on social care policy and wider policies related to the ageing population. In a policy era where there is emphasis on integration and collaborative care (Coalition for Collaborative Care, 2014), greater mutual understanding of terminology appears timely. Interestingly, very few participants working in home care or domiciliary services seemed to use the term frailty. This is despite evidence from Canada that frailty might be a shared characteristic of home care users (Armstrong et al., 2010). These authors caution against policy makers and professionals being over-reliant on measures that have been developed for older patients or care home residents because older people living at home are much affected by aspects in their social (e.g. family carers) and the physical (e.g. quality of housing) environment. They suggest that frailty measures should reflect more of a biopsychosocial or integrative approach if they are to be useful more broadly.

Summary

This article has shown that the term frailty was not commonly used by staff from social care services when talking about their clients or their work. Where it was used, many meanings were employed. Older people who are ‘frail’ were therefore being represented in different ways. The ‘problematisation’ of frailty needs also to include understandings of the many meanings attached to the term. In the current English policy context of sustained efforts to integrate services, exemplified by the NHS England planning and commissioning guidance ‘Safe, Compassionate Care for Frail Older People Using an Integrated Care Pathway’ (NHS England, 2014), those implementing such policies should be careful of presuming that language is shared and commonly understood. Policy makers may be advised to exercise caution in using terms such as frailty within statements, guidance and other communications about ageing and older people.

Acknowledgements and disclaimer

We are most grateful to the participants in this study and the interviewers. The Longitudinal Care Work study research team includes colleagues from the Social Care Workforce Research Unit, Shereen Hussein, Michelle Cornes, John Woolham, Stephen Martineau, Caroline Norrie, Kritika Sami and Janet Robinson, all of whom have contributed to the study design, data collection or analysis. The Social Care Workforce Research Unit receives funding from the Department of Health’s Policy Research Programme but the
views are expressed here are those of the authors alone and should not be necessarily interpreted as those of the Department of Health.

References


32


