It is a good thing that we understand diseases in a very detailed way – less impressive, however, is our understanding of how patients feel about them and live with them. Having a management plan for our patients' conditions has substantial benefits, but a deficit-based approach can also have a stigmatising and disempowering effect. With frailty and dementia, measuring and counting deficits is not enough – patients and carers need to be empowered to use their health assets and resilience. But first, what is health?

In its constitution, back in 1946, the World Health Organization (WHO) defined health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (www.who.int/about/mission/en/). In recent years, that definition has been challenged, the criticism being that aiming for complete wellbeing is unrealistic. As such, a new definition has been proposed; for Huber et al (2011), health is “the ability to adapt and to self-manage in the face of social, physical and emotional challenges”. The focus on ability, adaptation and self-management is key, as it puts the person at the centre of their health and wellbeing.

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Talking points

Living with frailty or dementia is not necessarily synonymous with living with health deficits

In frailty, considering health assets and resilience is essential to help patients and carers avoid following a downward spiral

The perception of frailty and dementia needs to include positive wellbeing and acknowledge the primacy of personhood

Embracing people’s assets and resilience is vital for self-management and behavioural change

Addressing the personal priorities of people living with long-term conditions could be more useful than fixating on interventions

Frailty and dementia: promoting health assets and resilience

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Abstract Characterising people simply through the problems arising from illness or the health deficits it causes, does not adequately take into account personhood or the complexity of multimorbidity. Frailty and dementia are two long-term conditions that need to be viewed in a more holistic way than solely through a biomedical lens. Rather than just measure and count health deficits to come to a diagnosis and treatment plan, it would be useful to recognise that health assets and resilience can improve the quality of life of people living with frailty and/or dementia and their families. This article discusses these issues and proposes that a ‘resilience measure’ is needed to complement the cumulative deficit model.

Frailty refers to a complex, multidimensional and dynamic state of diminished physiological reserves leading to:
- Decreased resilience;
- Reduced adaptive capacity;
- Increased vulnerability to stressors.
Whether it is a syndrome or an accumulation of deficits is still unclear (Clegg et al, 2013).

Dementia describes a set of cognitive and/or behavioural symptoms that include:
- Memory loss;
- Personality changes;
- Difficulties with thinking, problem-solving, language and other higher-order perceptions.
It results from diseases that damage the brain (Hodges, 2010).
Over the years, the diagnostic criteria for frailty and dementia, and the ways of measuring them, have evolved. However, both frailty and cognition exist as continua, so a binary approach – that is, someone lives or does not live with the condition – is not totally justified.

**Deficits versus assets**

Deficit-driven models work by identifying health needs and problems that are to be addressed using health and social care resources, and then by trying to reduce the levels of dependency on services. In dementia, the tradition has been to look for deficits in function; for example, loss of memory or language. The same tradition exists in frailty, when deficits may include loss of grip or muscle strength.

Deficits identified in a biomedical model are useful for professionals to agree on whether somebody has a certain diagnosis or is responding to therapy. They are also useful to monitor changes in the person’s condition over time and assess how severely a person is affected; for example, someone with more cognitive deficits will obtain lower scores on cognitive assessment scales. Identifying deficits can therefore be helpful; however, solely focusing on them can have negative effects on how people perceive themselves.

By contrast, asset-based models accentuate people’s strengths, resources, abilities and capacities so that problems can be identified and solutions can be found. This promotes self-esteem and motivation among individuals and communities, ultimately leading to a reduced reliance on professional services.

**Biomedical lens**

Diagnostic labels can be convenient shorthand, but frailty and dementia both have in common the fact that they rarely travel alone. In other words, it is unlikely that someone will just ‘be frail’ or just ‘live with dementia’. In fact, in older age groups, multiple morbidity is the norm – and unfortunately so is polypharmacy. This makes it less likely that a person will follow one single clinical pathway. Patients will often be conceptualised as a series of problems and health professionals will often consider that their primary duty is to fix illness. A deficit-driven approach is well suited to this.

However, people do not want to be defined by their illnesses, as they are much more than that – they are whole persons with a past, present and future outside of their illness trajectory (Brooker and Latham, 2016). Indeed, they are not so keen on labels such as ‘frail’ either: in a recent survey, most older people did not identify with the term ‘frail’ and tended not to use the word ‘frail’ or the phrase ‘living with frailty’ (BritainThinks, 2015).

Viewing people only through a biomedical lens can lead to disregard for personhood, as it equates to ignoring a person’s need to use their strengths and assets. When professionals fixate on what people cannot do, as opposed to what they can do, this is likely to cause tension and be profoundly demoralising.

**Health assets**

By using an over-medicalised approach to dementia and frailty, and by ruminating about cures that may one day be available, we may neglect other aspects of a person’s health where there may be potential for improvement in the short term, such as social wellbeing, social connectedness and social inclusion (Box 2). When we concentrate on the brains and bodies of people living with long-term conditions, we tend to ignore the wider ecosystem they inhabit – that is, their social environment.

Focusing on deficits means insufficient attention is being paid to health assets – these are the collective resources that individuals and communities have at their disposal and that protect them against negative health outcomes. In a state of equilibrium or relative wellbeing, health deficits are balanced by health assets. That concept is not new: Rockwood et al (1994) conceptualised a dynamic model of frailty in older people in which the balance between assets and deficits determines
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whether a person can maintain independence in the community (Fig 1).

Premature medicalisation

Strongly influenced by a biomedical model of irreversible decline, the way dementia and frailty are perceived by the public has led to widespread feelings of hopelessness and futility. Life can become medicalised even before symptoms appear – there is currently an emphasis on diagnosing frailty or dementia at the earliest possible stages of pathology, so people may find themselves having a diagnosis of frailty or dementia without any significant symptoms. Whether interventions in states of pre-frailty or pre-dementia are ethical or desirable remains an open question.

The biomedical model tends to pull us towards finding drugs that will stop diseases in their tracks. This may distract us from considering non-pharmacological approaches, such as helping carers or providing end-of-life nursing care. On the other hand, the fact that effective pharmacological interventions are currently lacking may demotivate patients and carers from approaching health and social care services and seeking a diagnosis in the first place – why bother?

However, receiving an early diagnosis of dementia or frailty can also help, for example, in preparing the future through advance care planning (Harrison Denning, 2017). It would be unfortunate if people living with frailty or dementia did not seek out reasonable adjustments for any disabilities they may have, as they would potentially miss out on support for themselves and their carers, as well as on opportunities to slow down the appearance of deficits by the adoption of health-promoting behaviours.

Cumulative deficit model

In dementia – for example, in Alzheimer’s disease – deficits are tracked by measuring memory and other cognitive functions. These deficits are attributable to pathology in the hippocampus and medial temporal lobe, so they can be revealed, for example, by an atrophied hippocampus.

With regards to frailty, the cumulative deficit model (Rockwood, 2016) defines it as a non-specific, age-associated vulnerability due to an accumulation of medical, social and functional deficits, and proposes that it can be measured by counting the individual’s health problems using a tool such as the Frailty Index (FI). A wide range of deficits can be measured, including symptoms, laboratory abnormalities and disabilities, although deficits must be acquired, associated with advancing age and associated with adverse health outcomes. Having more deficits is associated with a higher risk of adverse outcomes, including disability, transfer to institutional settings and death.

A hybrid term, ‘cognitive frailty’ (Panza et al, 2006), is used for states of vulnerability from dementia, such as mild cognitive impairment or multiple risk factors for vascular disease. Evidence for this derives from data supporting the existence of shared risk factors. For example, both impaired cognition and frailty syndrome are associated with cerebral infarction and high pro-inflammatory cytokines – such as tumour necrosis factor-alpha, interleukin-6 and C-reactive protein (Parolari et al, 2007; Ramlawi et al, 2006).

“Asset-based models promote self-esteem and motivation, ultimately leading to a reduced reliance on professional services”

However, although the cumulative deficit model is influential and has important clinical implications, simply counting the number of deficits leads to an overly simplistic view of frailty. Most people would agree that it is more complex. We do not know, for example, whether the chronological ordering of the appearance of deficits matters, or whether some deficits are more important than others. Furthermore, we may be tempted to focus only on the deficits at the expense of other aspects of health that may promote the person’s assets and resilience.

Lived experience

To understand the lived experience of frailty or dementia, it is crucial to explore how the conditions actually affect people’s lives, including, for example, their:

- Personhood;
- Interactions with others;
- Spirituality;
- Sexuality;
- Environment (shared spaces or the built environment).

Both frailty and dementia are good examples of complex adaptive systems, characterised by a level of uncertainty, non-linearity and unpredictability (Fraser and Greenhalgh, 2001), which is somewhat inconsistent with the apparent certainty afforded by a diagnosis and prognosis, as well as with the comfort of an intervention.

There is plenty of research on the effects that caring for a person with dementia has on their relatives (Newbronner et al, 2013), which largely stresses negative effects, including a physical, emotional and financial burden. However, there is relatively little literature on such topics as the coexistence of frailty and dementia among spousal carers (Ringer et al, 2017) or how health and social care could work together to help people build their resilience.
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Vulnerability and resilience

Individual socioeconomic circumstances affect older people’s health and wellbeing, as do the neighbourhoods in which they live (Wu et al, 2017; Lang et al, 2009). This may be described as social vulnerability, which, according to Cannon (1994), is a set of characteristics that include a person’s:

- Initial wellbeing (nutritional status, physical and mental health);
- Livelihood and resilience (assets and capitals, income and qualifications);
- Self-protection (capability and willingness to build a safe home, use a safe site);
- Social protection (preparedness and mitigation measures);
- Networks, power and culture (social capital, organisations).

The literature suggests that ‘vulnerability’ and ‘resilience’ are related (Box 3). We prefer to emphasise resilience. It is difficult to talk about frailty and dementia without referring to resilience. Resilience may be defined as “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or ‘bouncing back’ in the face of adversity” (Windle, 2011). Frailty and dementia can be clinically measured using standardised criteria, but so far resilience has escaped measurement.

Building resilience

We know that a higher level of education and good physical health are protective factors against the development of dementia. The risk of becoming frail is doubtless affected by health and lifestyle behaviours throughout life, not just in old age so, equally, we should look for interventions that can effectively build up resilience against falls, immobility and delirium.

Preventing delirium seems especially important, as individuals with delirium have a higher prevalence of frailty (Verloo et al, 2016) and frailty is associated with poorer functional outcomes and increased mortality in delirium (Eeles et al, 2012).

A frail individual is less likely to fully recover – for example, from a fall – than someone who is robust. The concept of pre-habilitation may be helpful here. Defined by Rumer et al (2016) as “enhancing the functional capacity of the individual to withstand a stressful event”, pre-habilitation has been found to improve post-surgical outcomes; for example, evaluating patients for frailty before a surgical intervention has enabled older – and potentially frailer – patients to successfully undergo organ transplantation (Rumer et al, 2016).

Asset-based approaches

An asset-based approach to practice, research and health policy (Box 4) aims to encourage professionals to help their patients maximise opportunities for health and wellbeing. This includes acquiring the necessary skills and competencies (Morgan and Ziglio, 2007); for example, people newly diagnosed with dementia could be actively encouraged to manage their brain health, including by exercising, improving their nutrition and lowering their risk of cardiovascular disease.

We also need to work actively with those carers who are themselves frail if we are to promote their resilience and boost their assets. For example, frailty is a major predictor of falls. Falls and fear of falling are interrelated and, together, can start a downward spiral of restricted activity, loss of ability, falls and increased fear of falling (Tinetti and Powell, 1993). Boosting somebody’s confidence could mitigate their fear of falling or avoidance of activity, thereby preserving their function and ability to care for another person. It is possible that people with a poor quality of life – that is, those who have poor health, more functional limitations and more limited social connectedness – develop greater fear of falling.

Community programmes

Asset-based approaches are not directly opposed to deficit-driven approaches but, instead, complement them. They can operate alongside interventions aimed at reducing health risk behaviours. Asset-based approaches can re-energise community programmes to come up with solutions for improving health and wellbeing through the recognition of individuals and organisations.

Ideally, health programmes for people with frailty or dementia are developed with and by local people, which makes them more likely to be successful and sustainable. Foot and Hopkins (2010) argued that community assets can achieve a number of goals, including:

- Providing new ways of challenging health inequalities;
- Valuing resilience;
- Strengthening community networks;
- Recognising local expertise.

Box 3. Vulnerability and resilience

- Frailty is a state of increased vulnerability to stressors arising from impairments in multiple body systems and leading to decline in homeostatic reserve and resilience. People living with frailty or dementia can take longer to recover from a stressor, such as illness, due to decreased resilience.
- The adaptive physiological response to acute stress is crucial for survival in life-threatening situations. However, the failure to resolve fully a physiological stress response upon cessation of an acute stressful event may lead to stress vulnerability.
- Vulnerability is made up of the characteristics and situation of a person or group that influence their capacity to anticipate, cope with, resist and recover from the impact of a natural hazard. Vulnerability to poor health outcomes is more common in advanced age. Social vulnerability in particular can be a risk factor for poor health outcomes and is an important aspect to take into consideration when looking at healthcare provision and planning.
- The emergent area of resilience has its roots in research on risk, stress and coping. Resilience is defined as an integrated process involving multiple peripheral and central mechanisms that promote an appropriate, non-pathological stress response. An individual’s resilience, confidence, meaning and purpose are related to the strength of their family, neighbourhood and social networks.

“People living with frailty or dementia have knowledge and experience that are powerful resources”
Resilience measure
The electronic FI (eFI) uses the cumulative deficit model as its theoretical framework; eFI scores are determined according to the presence or absence of individual deficits, and can possibly predict outcomes of mortality, hospitalisation and nursing home admission (Clegg et al, 2016). However, the danger from this reductionist approach is that we treat all deficits as equivalent to each other and, therefore, think that, by simply adding them, we can tell what will happen to a person. This overlooks the differences between individuals in terms of their resilience, assets and supports.

What may be required is a complementary ‘resilience measure’, which would draw on information about resilience, assets and supports. This would enable us to explore wider determinants of health. After all the reasons why someone with frailty and dementia moves into institutionalised care is more likely to be due to a lack of social networks than the sum of their symptoms.

The future is bright
For professionals, changing our mindset from an entirely deficit-driven approach is a challenge, but a more holistic approach to people’s health should be a priority for everyone in health and social care, and not be ‘siloed off’ somewhere in public health. Unfortunately, for the time being, deficit models are predominant in policy on frailty, the emphasis being on avoiding admissions rather than on improving people’s quality of life. This all escapes discussion somehow.

People living with frailty or dementia have knowledge and experience that are powerful resources. The asset-based approach brings environmental influences into the discussion of what is and what is likely to promote good health – the focus is less on interventions and more on personal assets and priorities for a better life. If we consider more the assets, resilience and resources of people who are living with frailty or dementia, they will have less that is ‘done to’ them and more that is ‘done with’, them.

We want to promote good lives and anticipate possible problems for people living with frailty and dementia, rather than reacting to problems in a crisis situation. Moving towards what can genuinely and cost-effectively promote wellbeing, thereby moving away from a discourse of accumulating deficits, will require flexibility and courage. Hopefully, adopting an alternative narrative will mitigate assumptions and stigma.

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