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Invited Editorial

Multimorbidity in people living with dementia

HIGHLIGHTS

- Multimorbidity is typical of the majority of people living with dementia.
- Healthcare systems are designed around single organ disease not multimorbidity.
- Guidelines for people with multimorbidity and dementia are hampered by a limited evidence base.
- Research to underpin new models of care is urgently needed.

Keywords:
Dementia
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Aging

1. Introduction

Multimorbidity has been variably defined but is generally taken to refer to a situation where an individual has two or more long-term health conditions. This working definition has been extended with the National Institute for Health and Care Excellence (NICE), expanding ‘long-term health conditions’ [1] to include:

- defined physical and mental health conditions
- ongoing conditions
- symptom complexes
- sensory impairments

Multimorbidity is important because it is associated with a poorer quality of life and increased risks of mortality, polypharmacy, adverse drug reactions, falls and hospital admissions. It is more common in older people and in those living with socio-economic deprivation [1]. Multimorbidity already affects two-thirds of the UK population aged over 65 and is projected to affect an even higher proportion. Despite this, healthcare is still designed around single organ problems - multimorbidity has implications for any re-organisation of health and social care. The situation becomes more challenging when an individual has both physical and mental health conditions and where their health complaints span this divide such as with dementia.

An estimated 50 million people worldwide were living with dementia in 2018 and this is predicted to rise to 152 million people by 2050 [2]. Multimorbidity is typical of the majority of people living with dementia and in one UK observational study a mean of 4.6 comorbidities in addition to dementia were identified. Conditions such as falls, osteoarthritis, diabetes mellitus, stroke, osteoporosis and heart failure were highly prevalent occurring in up to one-quarter of participants [3]. Dementia is more common in older women than older men; largely due to women living longer. Conditions such as osteoporosis, falls and fractures are more common in women and are more common in people with dementia. Indeed multimorbidity in general is more common in people with dementia [4].

Despite the projected rise in multimorbidity and dementia surprisingly little research has examined even the basic epidemiology of this growing population [4]. Healthcare, functional and social support for people with multiple health conditions is not straightforward and the addition of cognitive impairment adds a further layer of complexity. For future service development to best support the growing number of people with these conditions the first stage is to describe this population and to understand the interaction between dementia and other common comorbidities. Such an interaction is not simple and is highly variable.

Dementia has a complex relationship with other long-term health conditions which can result in a cumulative spiral of increasing risk leading to an adverse outcome. For instance, dementia is a risk factor for falls but also for osteoporosis - this results in a higher rate of fractures than might be expected from the intrinsic falls rate alone. In addition dementia is also associated with poorer recovery from fractures after the event; further compounding this issue [5]. Dementia also modifies the natural history of highly prevalent conditions such as hypertension. In contrast to the general population, systolic blood pressure has been observed to start falling up to 6 years before the development of clinically apparent dementia [6] and to continue to fall thereafter. The observed falls in blood pressure (of between 22 and 8 mmHg) have been potentially sufficient to move an individual below treatment thresholds. This interaction therefore has implications for the treatment and monitoring of blood pressure in people with dementia compared to the cognitively intact population [7].

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Person-led care has been a central element of NHS planning since the 1990s - seen as a key mechanism to improve the quality of care for people living with long term health conditions [8]. The NICE multimorbidity guidance advocates an individually tailored, goal driven approach with the aim of personalising care to match the aims of an individual patient. The guidance acknowledges that the management of multimorbidity (already far from simple) is more complicated in the presence of dementia and stresses a careful consideration of the benefits and harms of any interventions. However, the guidance is hampered by the historic exclusion of people with dementia from multiple trials. This extends to trials of self-management of long-term health conditions where the only identified study to include people with dementia was considered to have poor quality evidence [1]. The treatment goals of an individual with dementia may change over the course of their cognitive diagnosis. Thus when mildly impaired, preventative medications such as antihypertensives may be desired, but in later stages of the disease treatments which prioritise quality of life over quantity may be more valued. People living with dementia and multimorbidity may therefore be trying to weigh up the benefits and harms of a treatment in the absence of a robust evidence base in a situation where their own goals may change with time and where their capacity to make such a decision may become blurred.

2. Conclusion

In the coming years there will be a growing population of people living with dementia and multimorbidity. Multimorbidity is already the majority lived experience of those aged over 65 in the UK and service provision is struggling to adapt to this situation despite multiple re-organisations of healthcare provision.

For the majority of practitioners it is now self-evident that managing multimorbidity should be person-centred and goal driven. The potential benefits and harms of pharmacological and non-pharmacological interventions should be discussed and compared as part of routine care. Such conversations are not without difficulty - the capacity to make such a treatment decision, the treatment goal and perceived benefits and harms may change with time and this will continue to be an issue in supporting people with dementia. However, the chief difficulty in such discussions, and I would argue part of the reason for the slow adaptation of the healthcare system to this challenge, is the lack of evidence base particularly for those living with dementia.

To support the development of appropriate healthcare systems, to support practitioners caring for people with dementia and multimorbidity and to support the people themselves it is now essential for a firm evidence base to be developed. The first stage must be to gain a more robust understanding of the functional, cognitive and medical impairments experienced by people with dementia. In part this could be carried out through large scale epidemiological studies using big data but it also requires a more personalised approach with detailed phenotyping of a cohort of people living with cognitive impairment. Such information could then help underpin the urgently needed evidence base to support better clinical decision making and systems design for people with multimorbidity and dementia.

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