'Addressing the global challenge of multimorbidity': oral evidence session

Dr Lynne Corner and Professor Stuart Parker, leads on the James Lind Alliance Priority Setting Partnership on Health with Multiple Conditions in Old Age at Newcastle University.[1]

Professor Parker began his presentation by explaining that he is a geriatrician, interested in how ageing, and society, is changing. He is a National Institute for Health Research (NIHR) Speciality Cluster Lead for Ageing, and for Dementias and Neurodegeneration.

Professor Parker explained how he was part of the 85+ Study team in Newcastle. This focused on 85 year olds, the fastest growing portion of the population, and their experience of the opportunities and burdens associated with changes in how we age. The team learned that these patients had an average of five diseases. Some had significant disability but good health-related quality of life, and would say that their health is good or excellent – he noted that this challenges perceptions of the burden of multimorbidity.

Dr Corner is Director of Engagement at the Newcastle University Institute for Ageing and Faculty of Medical Sciences. She explained that she is interested in frailty, later life, and dementia and understanding the patient perspective. She noted that as patients get older they become more different – therefore chronological age is not the key issue to consider, but patient circumstances and experience is as important. She added that she has a particular interest in understanding the priorities of patients, and their carers and family.

Dr Corner directs Voice North, an organisation dedicated to harnessing the insights of older people and involving patients in ageing research.[2] She explained that the public and patients are real assets and partners, and it is useful to understand what they want to achieve when setting research priorities.

Q1. How do you engage with patients?

- We are currently leading a Priority setting exercise with the James Lind Alliance - engaging with patients and carers to understand their priorities.
- Voice North is extending its work to understand patient priorities in new areas.
- From work with Voice North we have undertaken, there is a large group questioning whether primary care is the best place to manage multimorbidity, given the complexity of five to seven conditions, and asking whether secondary care experts can better manage this complexity but in the community.
- There is huge diversity in patient aspirations, ranging from 50 year olds with a life limiting illness to 85 year olds in great shape.
- Patients express a desire to see and discuss evidence and research for new outcomes. For example, some are asking about the possibility of a third hip replacement, if living significantly longer.
- One core finding is that when discussing multimorbidity patients focus on symptoms and consequences of conditions, such as breathlessness or not being able to climb stairs, rather than simply focusing on the conditions causing them (e.g. COPD). Seeing 'every day' improvements in discrete symptoms, as opposed to clinical measures of disease, is therefore what patients consider of importance - quality of life is key.

[1] https://research.ncl.ac.uk/jlaprioritysetting/ageingmultimorbidity/
[2] http://www.voicenorth.org/

It is also important to understand the difficulties and concerns experienced by those who care for patients with multimorbidity. This may be emotional, although the financial burden on carers can also impact on their ability to live later life to the full. There are very complex implications, and we simply don't have enough evidence in many areas.

Q2. Has information from Voice North helped to define important research questions?

- The first step of the James Lind Alliance process is to review previous Priority Setting Partnership questions, of which there are around 700, to determine which are relevant to older people with multimorbidity. There are three or four relevant questions, but overall this is a new dimension, which is not surprising given the previous focus has been on single disease or conditions.
- Qualitative research from patients and carers feeds into priority setting.
- A series of consensus setting meetings are being held, leading to a long and short list which will be released over the course of this year.

Q3. How can we quantify and tackle inequality, such as the highly variable access to hip replacements?

- Understanding how inequalities influence how receptive patients are to interventions requires more research focusing on patient priorities. It is important to remember that patients rationalise information differently from clinicians, and often make decisions that are not wholly evidence based. For example, a need to continue to work or care will influence their decisions alongside medical evidence and recommendations.
- One strong fear expressed by members of Voice North in the UK is age-related rationing, yet if we scale forward then we'll have a large group of patients who are not fit to work but still need to work as the retirement age continues to increase.
- The older age group also has a high care burden. Fitness to care is also key.
- We need to have an open mind to surgery later in life, due to the possibility of quality of life improvement, for example cataract operations in those with dementia.
- Co-morbidity 'muddies the waters' in trials and is traditionally excluded, so we find ourselves working in ways that are underpinned by a relatively sparse evidence base.

Q4. Do the patients involved with Voice North see themselves as having multiple diseases, or one major disease alongside several others? Would it be helpful to consider the patient's priority condition?

- The patient perspective is that not all conditions are equal. The combination of diseases really matters. How to tackle this is a major issue.
- If patients are struggling to cope at home, there are many opportunities to help. If a patient has difficulty getting upstairs, we need to focus on the pathology that is causing this presenting problem.
- We need to unpick the reasons for long-term admission to care, as this can reveal disparities between what patients and clinicians consider to be of primary importance. For example, one major trigger for long-term admission is incontinence, especially faecal incontinence, rather than necessarily a patient's dementia – this issue matters more to carers. Mobility is another major issue.
- A key finding is that non-clinical interventions - including environmental and technological changes - can also help create improvements in quality of life, e.g. design of bathrooms is as important as clinically addressing continence.
- Polypharmacy is also a major issue for the elderly. Of a sample of Voice North members, 90% are taking ten or more tablets. Around one quarter are on these for at least 15 years, and

people are not clear of the interactions. A stark finding was that most people don't know what particular tablets are for. There is a lot of confusion over drugs, their management, where to get advice, and long term interactions.

Q5. There are a growing number of sedentary and obese patients. Is this already affecting patients in old age?

- We need more evidence to address this question. We cannot generalise by age. This 85 year old cohort is fitter than younger cohorts following them.
- Voice North explored the exercise advice patients are given. With age, this flips to worry that exercise, especially intensive exercise, actually could cause harm. Fitness for surgery is a key concern and people wanted more evidence on this.
- We need to know more about exercise beliefs later in life.

Q6. Is there a public sense that medications can cause harms?

- We need more evidence to better understand how patients receive health related messages. For the Voice North group, numbers don't match for prescribed versus taken drugs; there could be patchy evidence as a result.
- Voice North members are very concerned about the combination of drugs, especially citing anti-angina drugs. More tailored advice, such as what to do if you miss taking a tablet, is required.
- There is increasing patient demand for 'softer' non-pharmaceutical interventions, such as physiotherapy, alongside standard interventions. However, this is not always affordable. For example, people needing physiotherapy, chiropody, osteopaths etc could have significant costs – up to £150 per week - which is unachievable for a majority of people.
- There is demand for more information, particularly regarding prioritisation. Patients tend to be more concerned about potential harms than benefits – for example both from taking drugs, but also from *not* taking drugs.