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Guest Editorial

It's time to acknowledge that much of what we practice and preach about dementia can be uncertain

Various different factors are crucial in living and dying with dementia. Intuitively, perhaps, we prefer 'facts' and 'certainty' – and this appears to be culturally important for convincing others that we know what we are talking about. However - many people might not actually wish to admit it, but risk and uncertainty are actually utterly pervasive throughout the whole of the dementia care. In research, there is a bit more lee-way in admitting we are not sure of the answer. The fog surrounding dementia begins with the combination of a factors in the life course which set a dementia process in motion, to the uncertainty whether somebody is in the final 48 hours of life, and even beyond.

Risk and uncertainty are not just key themes in healthcare. Frank Knight was the economist famous for proposing a distinction between risk and uncertainty in his celebrated 1921 book, "*Risk, Uncertainty, and Profit*". As Knight saw it, an ever-changing world brings new opportunities for businesses to make profits, but this also means that we have imperfect knowledge of future events. Therefore, according to Knight, risk applies to situations where we do not know the outcome of a given situation, but can accurately measure the odds. With dementia, risk as a guiding concept for practice is problematic because cannot easily quantify the "odds" of certain events happening. Acknowledging the uncertainty of outcomes may be a more useful perspective in circumstances such as somebody developing dementia as a result of life events, somebody not coping as a result of becoming a family carer due to lack of personal 'resilience', somebody with dementia developing terminal delirium in end of life and dying. Uncertainty might result because we have imperfect information about the factors determining outcomes, have a lack of understanding how different factors interact to produce outcomes, or simply lack the sophistication to cope with the complexity of calculating how factors interact to produce outcomes.

This special issue of dementia care research for the International Journal of Nursing Studies is, to me, an exploration of a number of burning contemporaneous issues in research in dementia care, and very timely. In many ways, it provides a snapshot of important 'yardsticks' in the current global literature. Dementia, rather than being a dry niche academic and clinical discipline, profoundly affects immediate family members and close friends, especially those who are involved in the caring process, at a deeply personal level. Often unpaid family carers, like me in fact, feel as if they are experiencing multiple losses and they are unable to fully mourn each loss. And the losses do accumulate very quickly. Carers often undergo considerable and significant psychological, social and quite existential challenges as they witness the progression of the disease in their loved ones (van Wijngaarden et al., 2018). I felt I learnt a huge amount from reading the papers in this special issue through that prism of being a carer, albeit a privileged one with a research and clinical background in dementia.

One of the big problems of supporting people living with dementia and their family carers, inevitably, is that clinicians dislike talking about uncertainty, preferring instead to be able to help with planning for a certain future. But needing to acknowledge the uncertainties of dementia is actually pretty unavoidable.

Fiona Godlee (2017) writes:

> "The only certain thing about medicine is its uncertainty. Patients and doctors must make decisions on the available information, which is always incomplete, variably relevant to individual circumstances, hedged around with likelihoods, best bets, and gut feelings, balanced by individual preferences, and constrained by available resources. Somehow, sometimes, good decisions are made." (page 358)

In terms of wider philosophy, and highly relevant to the world of strategy analysis and implementation so germane to wider policy, Herbert Simon introduced the term '*bounded rationality*' (Simon, 1957: 198) as a shorthand for a brief against neoclassical economics, as part of his call to replace the perfect rationality assumptions of *homo economicus* with a conception of rationality tailored to cognitively limited agents. 'Bounded rationality' has since come to refer to a wide range of descriptive, normative, and prescriptive accounts of effective behaviour which depart from the assumptions of perfect rationality (Stanford Encyclopaedia of Philosophy, 2018). And it is this bounded rationality which needs to be considered when we think about analysing strategy in dementia, whether in research or in practice.

1. Uncertainty in the diagnosis and the future of that diagnosis

Everything from prevention to dying with dementia is fraught with uncertainties. We do not know the '*perfect storm*' amongst genetic and environmental factors across the life course which cause individuals to develop dementia, perhaps over a period of decades even. For most people, the disclosure of the diagnosis of dementia turns out to be a paradoxical experience fraught with uncertainty; it gives some degree of certainty and takes away agency to variable degrees simultaneously. For many, the

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disclosure of the dementia diagnosis *causes* very uncertain and unexplainable episodes to come to an end.

Whisper it softly. We do not know the exact significance of the entity of mild cognitive impairment ("MCI"). The study by Petry et al. (2019) includes people with MCI, but even this diagnosis is 'complicated' as it is conceptualised as a stage in between normal cognition and dementia. At worst, it is a diagnosis given by some clinicians who cannot make up their mind whether a person has dementia or not. There has been growing interest in the condition of MCI over the past two decades or so because people with MCI are claimed to be more likely than people with no cognitive impairment to progress to dementia. But it is indeed worth noting that a significant percentage of people with MCI will not progress to dementia and some will revert to having normal cognition (Mukadam, 2018). Rates of progression and reversion to normal cognition vary widely in different studies (Manly et al., 2008). With mild cognitive impairment, the involvement of confounding variables currently also remains unclear, and adds a further level of uncertainty to research. Song and Yu (2019) claim: "*future studies should consider long periods of follow-up to evaluate the effectiveness of exercise interventions on delaying or preventing the onset of dementia*". This is indeed true - but it is unfinished research as to whether this possible beneficial effect of exercise on cognition might be through another entity such as frailty?

2. Uncertainties in care for the needs of people with cognitive impairment

National and international dementia care policy has invariably focused on the most effective mechanisms for post-diagnostic care and support.

For example, in the UK, there is now uncertainty what the future will bring regarding resources for acute hospital care, given also the monies being put aside for "Brexit". There are a third fewer general and acute beds now than there were 25 years ago, but the last decade alone has seen a 37% increase in emergency admissions. UK hospitals have traditionally coped with this increase by reducing the average length of stay for patients. However, this fall in length of stay has flattened and in the past three years it has started to rise for patients over 85 (Royal College of Physicians of London, 2010). Emergency hospital admissions of older people are increasing globally, and are likely to continue to rise given current demographic trends. Dementia rarely travels alone, and a short length of stay may not promote patient safety. This is, whilst length of stay might be a desirable management outcome superficially, dealing with so many complex comorbidities comprising somebody's decline in health may not be easily feasible in a short space of time.

Against this backdrop, there continues to be active discussion about the most effective way to deliver integrated, person-centred care. Older adults now comprise around two-thirds of hospital inpatients, and up to 50% of these patients have some form of cognitive impairment, including that related to dementia. Petry et al. (2019) are absolutely correct to state that an "*older person with cognitive impairment and their family members' complex and specific care needs are insufficiently met*", and this may be, fundamentally, due to an underestimation of the impact of complexity, comorbidity and polypharmacy, as well as a failure to embrace all aspects of person-centred (and both relationships-centred and family-centred care) including effective communication and understanding of personhood. The fresh study by Fogg et al. (2019) in this journal is extremely significant and welcome contribution to the literature, as it enquires: "*Possible mechanisms for the increased risks observed in patients with cognitive impairment include differences in effective care for people with cognitive impairment in hospital, and intrinsic mechanisms which place these patients at higher risk of deterioration.*" One gets the sense that the "system" is not "out to get" those people with cognitive impairment, but due to a range of factors the "system" happens to be particularly disadvantageous, and possibly discriminatory, to them.

The paper by Fogg et al. (2019), however, is likely to be part of a much larger challenge of working out the nature of many important inter-relationships, such as between frailty and cognitive impairment, and between delirium and dementia. That paper is useful as it notes a number of comorbidities, as well as the observation that: "*[the] study also highlighted that patients with cognitive impairment were the most likely to have two or more ward moves during their hospital stay*". One is cognisant that an acute hospital stay can itself might be very delirium-ogenic. And this is wrong - every clinically-preventable deterioration for a person with cognitive impairment, for example through delirium and associated suboptimal 'care', is a personal tragedy.

And quite rightly the culture of acute care is brought under scrutiny. As the old saying goes, 'culture eats strategy for breakfast'. People with dementia can find themselves being disempowered (Featherstone et al., 2019): "*People living with dementia, were often very capable of many types of self-care during their admission (eating meals, walking independently, being continent). However, this was typically independence that was undermined by the type of care on offer, denied by the organisation of timetabled delivery of care within the wards and this had a further impact on shaping ward staff understandings of dementia. Staff appeared to expect that people living with dementia would need support at mealtimes, be unable to walk independently, and be at high risk of falling, with often presumed incontinence. This led to routine practices of care that increased staff workloads and also limited opportunities for people living with dementia to rehabilitate and increase their independence*." This risk averse nature in care *can be* bad for your health. Well intended motives, such as not mobilising patients with delirium for fear of falls, can have dire consequences such as profound deconditioning. For family members, having access to staff and information, being recognised as an important other, experiencing involvement in care processes, and receiving support was at the core of their acute care experience (Handley et al., 2019).

3. Uncertainties in the world of carers

Those who care for people with dementia must constantly navigate this tension between continuity and change within the context of cognitive changes of a person living with a cognitive impairment such as dementia, knowing when to respond by reinforcing the 'self' they have known over time, and when it may be better to respond by acknowledging the changes that have taken place within the context of that 'self' (Orr and Teo, 2015). Over the years, the difficulties and risks inherent to the role of family carer of a person with dementia have been examined in numerous studies, tending to emphasise a complex interplay of physical, social and behavioural functioning (e.g. coping and adaption strategies). With cognitive changes come increased dependence. It is uncertain to carers like me how independent a person with dementia can be, assuming that independence is not a binary construct. Liu et al. (2019) support the notion that the quality of mealtime environments has been much underemphasised in dementia care: "*Staff need appropriate knowledge and skills to effectively interact with residents who need mealtime assistance to optimally engage residents in eating, maintain maximal functional independence and improve nutritional intake. . . . The study findings provide directions for the development and testing resident-centered mealtime assistance and staff training programs targeting multifaceted aspects of a successful mealtime experiences by emphasizing the role of resident eating performance, staff facilitation, as well as eating*

and drinking activities." I myself have argued for a person-centred approach to eating well with dementia (Rahman, 2015).

The study by Lee et al. (2019) is fascinating. They use the approach of 'transition theory' to understand family caring, with a focus on reactions of carers toward changes in their own roles and the factors that may influence their health as they adjust to altered circumstances following diagnosis. This is no trivial matter, as carers can go themselves into a meltdown through their rôle. The authors conclude that their research "*demonstrates that during this period of transition, caregivers experience changes upon diagnosis, including changes in their relationship with the recipient of care and new roles and responsibilities*." It is hypothesised by them that caregivers need information about the disease and available resources and assistance with planning care, as well as emotional support resources. However, *anticipating* the future is very different from *predicting* the future. The study by Lee et al. (2019) is especially compelling, as it gives people that scarce resource: "hope". They hypothesise that suitable interventions may support caregivers during transition following dementia diagnosis with tools and resources such as information, education, psycho-social support, and enhancing problem-solving skills.

Much has been said previously about advance care planning, but it is reasonable now to argue that this is not an exact science. The complexities associated with advance treatment decisions may result in some degree of decisional uncertainty and poorly informed choices, particularly among vulnerable populations. This is especially relevant to such as patients from various ethnic minorities and to patients with limited health literacy. Culturally sensitive, literacy-appropriate tools are needed to address decisional uncertainty and to help patients prepare for decision making about their future health care (Sudore et al., 2010), and this is especially important as we try to draw conclusions across various jurisdictions.

It is perhaps striking that the process of decision-making in Japan usually results in decisions being made *for* people living with dementia mainly due to the lack of early discussion between the patient, family and healthcare professionals and importantly, patient's overreliance on others to assume the decision-making role (Miyanaga and Poudyal, 2019). It is mentioned that in a survey of middle-aged and older adults, only 12.7% had decided preference of their own care, 31.9% had ever thought but not yet decided and 52.3% had never thought of advance care planning (Arai and Arai, 2008). Bolt et al. (2019) further talk about uncertainties in palliative care. Nursing staff needs in providing palliative care for people with dementia involve recognising and addressing care needs (mostly physical pain), verbal and non-verbal communication, and dealing with challenging behaviour. Interesting, they comment: "*Nursing staff struggle to apply a palliative approach according to the established domains of palliative care in dementia*". This is inevitably disappointing as palliative care is fundamentally person-centred care. Hsieh et al. (2019) report that the possibility of six prognostic predictors of 6-month mortality among residents with advanced dementia in Taiwan. These predictors may serve as risk assessment indicators for nursing staff who provide clinical care and can enable the identification of patients in recognised terminal decline, thereby allowing access to hospice palliative services.

4. Uncertainties in direction of policy

The uncertainty as to whether non-pharmacological interventions are preferable to pharmacological interventions is an important one.

There are two interesting examples of this difference in approach in this special issue. Firstly, although the efficacy of massage for behavioural and psychological symptoms of dementia has been investigated in numerous recent studies, the actual strength of the recommendation in guidelines for dementia remains weak. It turns out manual massage may serve as a non-pharmacological strategy to improve behavioural and psychological symptoms in persons living with dementia, so healthcare professionals and family caregivers should be encouraged to apply massage to their patients and relatives (Margenfeld et al., 2019).

Secondly, another consistent observation has been that coping strategies are a lifeline for carers. Again, non-pharmacological interventions, rather than chemicals, are likely to be in pole position in caring for carers For example, Kor et al. (2019) report that a modified mindfulness-based cognitive therapy program provides carers with the skills to practice mindfulness when facing stressful situations, which can empower them to face the everyday challenges of caring for people with dementia.

5. The exquisite existence of uncertainty

There is a plethora of various factors involved in living and dying with dementia, not least the effect of the environment on the person with dementia. As Malterud et al. (2017) state, "*Clinical practice must therefore develop and rely on epistemological rules beyond prediction and accuracy, acknowledging uncertainty as an important feature of knowledge and decision making*." There is arguably not a clear division between what can be predicted with certainty and what cannot be (e.g. Roser, 2017), and this is a problem across all of research and practice in dementia. This means we do not instinctively know which dementia diagnoses we can predict with absolute confidence, even perhaps early dementia which follows a familial pattern of inheritance. We cannot tell with confidence what the prognosis of a person with dementia might be, or might be the ultimate challenges in determining the outcome of an advance care plan. This might seem like bad news. We can't predict which unpaid family carers will have a crisis.

But the good news is that the more we identify what factors are important in living and dying with dementia, and why and how they interact, the more we can do to mitigate the negative outcomes of these factors.

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