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Guest Editorial

Dementia care research: The key role of nurses and nursing



It has long been recognised that while finding cures for the various disease processes underpinning dementia is highly desirable, significant research effort also needs expending on informing prevention, risk reduction, diagnosis, treatment and care (World Health Organization, 2017). Given nurses' frontline role in the organisation and delivery of services to people at risk of and living with dementia worldwide, nursing has a key role to play in the research community delivering on this broad and complicated agenda (Ministerial Advisory Group on Dementia Research, 2011). This special issue of the International Journal of Nursing Studies focuses on dementia care in particular, and includes high quality research that draws attention to the contribution of nurses and nursing in high quality health care for men and women living with dementia. We invited and selected papers reporting the evaluation of interventions in which nursing plays a key role and that are focused on improving dementia care quality. We have also included papers that report research on the organisation and delivery of dementia care, and that improve understanding of the requirements for health systems that support high quality care delivery. The breadth and quality of contributions to this issue demonstrate that nurses are an important part of the research effort in care research, but a step-change in contribution to the field is still needed, including shaping investment, funding and capacity-building in the field.

As a nurse, as a family member and as a friend, I have experienced and witnessed first-hand the impact that dementia has on people's lives. I have also learned how clinical practice and research focused on disease alone is only part of the picture. We need to generate research evidence that drives sustainable change and improvement targeted at bettering a significant number of people's lives, regardless of stage of disease progression. Science is required that is grounded in the everyday complexities and experiences of men and women living with dementia, their family carers and frontline staff providing care, that identifies the enablers and barriers of change in a complex adaptive system, and that makes possible carefully designed and evaluated innovations and evidence-based implementation plans. At the heart of such research and in clinical practice, nurses and nursing need to champion rights-based approaches that actively promote the rights of men and women living with dementia to participate fully in the world, including in research, to have their needs made visible at a population health level, to easily access health and social care services tailored to their needs, and to be supported to make decisions and take risks to maintain or improve their quality of life (Bartlett and O'Connor, 2010).

Dementia complicates healthy ageing, health care utilisation and the outcomes of interactions with the health system (such as hospital visits). Research in this special issue and wider has improved our understanding of the experiences of people with dementia and the role played by interventions and services that nurses may be involved in delivering (Lee et al., 2019; Margenfeld et al., 2019). It has highlighted the inadequacies of health and social care systems and services to meet people's needs when dementia is in the picture, in spite of evidence of poor outcomes (Featherstone et al., 2019; Fogg et al., 2019; Hsieh et al., 2019). It has also shown how the care experiences of individual patients and family carers are shaped by the way that services are currently commissioned, organised and delivered (Featherstone et al., 2019; Petry et al., 2019). As emphasised by Kristiana Ludlow and Jeffrey Braithwaite in their editorial accompanying this issue, underlying these experiences is a nursing workforce that may be ill-prepared and inadequately resourced to deal with people living with dementia (Ludlow and Braithwaite, 2019). This is in addition to a lack of integration of services and a health system largely configured to address the needs of patients who present with a single, curable medical issue (Bolt et al., 2019; Handley et al., 2019). Transformation of health and social care delivery, drawing on innovations in systems design, service models and technology, and effective engagement with wider social networks, is urgently needed to create a care system that is sustainable and that meets the needs and expectations of the service users and their families, especially of people living with the most complex needs associated with ageing and dementia.

In the UK and elsewhere, policy and practice developments in many dementia care and technology areas are proceeding apace on a limited evidence base (Daly Lynn et al., 2017; Dawson et al., 2015; Livingston et al., 2017; Pickett et al., 2018). Much of the evidence base focuses on therapies for individual patients targeted at slowing disease progression or addressing dementia symptoms, but we understand little about the daily challenges of living with the complexities of dementia, especially when comorbidities are present, when disease is more advanced and/or when end of life approaches (Dawson et al., 2015; Knapp et al., 2013; Pickett et al., 2018; Snowden et al., 2017). Involvement, recruitment and research methods that can capture the perspectives of men and women living with dementia are available, but are not routinely deployed, and so these important perspectives are missing from much of the care and technology research to date (Bartlett et al., 2018; Bridges et al., 2018; Daly Lynn et al., 2017; Dawson et al., 2015; Lourida et al., 2017). There is a recognised translational gap

in many parts of the field, for instance, general hospital care, where research evidence rarely translates to routine practice (Knapp et al., 2013; Lourida et al., 2017). Because of a lack of research into the phenomenon of innovation itself, and a lack of attention in research and development to complexity, the generation of new evidence in this field that has the potential to transform people's lives rarely results in concrete, widespread and sustained changes for people living with dementia (Knapp et al., 2013; Lourida et al., 2017; Pickett et al., 2018). In addition, there are research studies, data and expertise highly relevant to this field, including in neuroscience, but which to date have not been applied to dementia care (Marjanovic et al., 2015).

Complex adaptive health and social care systems have multiple elements at system, service, team, frontline practitioner and service user level interacting and behaving in ways that cannot always be predicted. The “postcode lottery” of irregularly configured and resourced services across countries and populations, the complex networks between service providers at individual, team and service level, and the diversity in available workforce and technology all contribute to the variability of outcomes for people living with dementia. Dementia itself is also a complicating factor at the individual level, highlighted by Shibley Rahman's editorial focusing on uncertainty (Rahman, 2019). Dementia is complex in the way that dementia types, disease progression and symptom profile vary between individuals over time, and also in the way that these elements interact with who they are as a person, with other health and social needs and the resources, including social networks, available to that individual and supporting family carers to meet these demands and maintain well-being. This complex picture means that care innovations that just focus on what therapy should be administered are unlikely to succeed or be sustained for all individuals that have the potential to benefit. When we consider dementia care improvement through the complexity lens, it opens up new possibilities for science, and new opportunities to make a difference with care (Braithwaite et al., 2017). The use of theories of cumulative complexity, burden of treatment, social networks, organisational behaviour and implementation to inform our research will enable us to ground our science in the everyday complexities of living with dementia and to better understand how to make improvements (Mair and May, 2014; Shippee et al., 2012; Vassilev et al., 2014).

It is clear that a sustained multidisciplinary effort is needed to achieve research and improvement at this scale and significance, and that nurses and nursing have an important part to play in shaping and delivering research. This includes adequate representation on strategy and funding bodies. It also includes creating pathways for practising nurses and nurse researchers to get involved and stay involved in dementia care research. The research showcased in this special issue highlights the breadth and quality of research already underway. To ensure, however, that the care available meets the needs of individuals living with dementia requires a serious and sustained step-change in nursing research effort and investment.

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