

Dementia Care in Australia – Policy, Practice and Research

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Abstract

Dementia is estimated to be the fourth leading cause of the overall burden of disease and the second leading cause of all deaths in Australia (Australian Bureau of Statistics, 2016). This paper reports an interview with Laureate Professor Robert Sanson-Fisher from the University of Newcastle, Australia. The purpose of the interview was to share with readers on the policy, practice and research of dementia care in Australia. The paper highlights the key principles in the Australia's National Framework for Action on Dementia, the concept of patient-centred care, journey for families and support people, end of life care, and research development in dementia care. International and interdisciplinary collaboration is essential to generate global solutions to improve the lives of people living with dementia and their families.

Keywords: Dementia care research, patient-centred care, care for caregivers, end of life care

Introduction

Dementia was estimated to be the fourth leading cause of the overall burden of disease and the second leading cause of all deaths in Australia in 2014 (Australian Bureau of Statistics, 2016). It is estimated that 353,800 people are living with dementia. The number of people with dementia is projected to triple by 2050, reaching around 900,000 people (Australian Institute of Health and Welfare, 2012). This paper reports an interview with

Laureate Professor Robert Sanson-Fisher from the University of Newcastle, Australia. The purpose of the interview was to share with readers on the policy, practice and research of dementia care in Australia with discussion supported by policy document and published literature. The paper highlights the key principles in National Framework for Action on Dementia 2015-2019, the concept of patient-centred care, the journey for families and support people, end of life care, and research development in dementia care.

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The key principles underpinning the National Framework for Action on Dementia (NFAD) 2015-2019

The NFAD is a key document that drives dementia care policy and practice in Australia. It was put together for the period of time from 2015 until 2019. The purpose of the Framework is to guide the development and implementation of actions, plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers (Australian Health Ministers Advisory Council, 2015). It represented the input of a wide range of consumer groups and people with expertise in the care of people with dementia and their support persons. The Framework presents seven priority areas for action (Australian Health Ministers Advisory Council, 2015):

1. Increasing awareness and reducing risk
2. The need for timely diagnosis
3. Accessing care and support post diagnosis
4. Accessing ongoing care and support
5. Accessing care and support during and after hospital care
6. Accessing end of life and palliative care
7. Promoting and supporting research.

The NFAD argues and advocates for the view that a dementia diagnosis does not mean that you hand over your citizenship rights at the same time. As a society we need to ensure that people with dementia continue to be treated as valued members of society. We should acknowledge that families and carers begin a new and difficult journey of their own. They have to try to cope with the emotional impact and implications of a diagnosis. They may also have to support changed behaviours and associated psychological symptoms of dementia, all of which can impact on their own wellbeing. Research shows that many family carers of people with dementia experience significant strain, stress and psychological illness such as clinical depression. Depression has been reported in 15-30% of carers of people with dementia compared with 17% in non-carers

(Cuijpers, 2005; Schulz, O'Brien, Bookwala, Fleissner, 1995). We should ensure that we have an expert workforce who is able to attend to the needs of these groups, and that investment in the workforce is viewed as favourable in order to achieve the goals of patient-centred care. The NFAD also argues that we need to plan for end of life, palliative care, and ensure individuals have advanced directives. We need to make sure that legal and social requirements are met. It is a far-reaching document in Australia and one which provides overall guidance to our work in the area.

Patient-centred care in people living with dementia and their caregivers

There has been a lot of discussion on patient-centred care in health care provision. There is a need to understand the meaning of patient-centred care in people living with dementia and their caregivers. Patient-centred care is a concept which has been derived from the Institute of Medicine (IOM) (2001). It argued that the health system could be reinvented to foster innovation and improve the safety, cost effectiveness and quality of care. There are six aims for improvement, such as safe, effective and timely, and one of them was patient-centred care. Patient-centred care has the following components: respect for patients' values, preferences and expressed needs; coordination and integration of care; information and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; continuity and transition; and access to care (IOM, 2001). In Australia a patient-centred care approach is supported by the Charter of Health Care Rights, the Australian Safety and Quality Framework for Health Care, and the National Safety and Quality Service Standards, plus a range of other jurisdictional and private sector initiatives.

Patient-centred care is as relevant to people with dementia as it is to any other patient population group. Engaging patients in the care process, giving them ready access to information, being able to design care processes to suit patients' preferences and

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needs, and developing mutual commitment to quality health outcomes, is what patient-centredness is all about. Patient-centred care provides a framework and guidance in relation to supporting people with dementia. It suggests that a diagnosis be conveyed in a dignified and timely manner, and in a way that the individual and the support person can understand.

Research in Australia indicated that symptoms of dementia were noticed by families on an average of 1.9 years prior to the first health professional consultation and there was an average of 3.1 years between recognition of first symptoms and obtaining a diagnosis of dementia. For some families the reality of a diagnosis of dementia is one of relief; they finally have a 'name' for something that has been going on for a while. People from non-English speaking backgrounds were diagnosed much later after the first onset of dementia symptoms compared with the rest of the population (Phillips, Pond, Goode, 2011).

There is debate that the period from symptom detection to diagnosis should be lessened so that people can get the diagnosis as early as they want. Advocates promote that it allows individuals and families the opportunities to make a range of lifestyle choices ahead of time, while individuals still have the capacity to do so.

An important ingredient of patient-centred care is that it should be responsive to the individual's needs. It is not the health care provider who should determine what happens. It is the person with dementia and the carer who should decide, such as whether they get information about diagnosis, and where they get information about the consequences of dementia. The idea of patient-centred care is essential for delivering high quality care. It also determines the research that we should undertake.

Care for family caregivers

Most individuals with early or middle stages of dementia are cared for at home,

usually by family members, or caretakers, which is very common in Asian cities like Hong Kong or Singapore. The impact on the family as a result of caring for a person with dementia can be great in both developed and developing countries. However, socio-economic and demographic changes lead to changes in family structure and the care that can provide by the family. The challenge is to find solution to substantiate the care for people living with dementia (Chan, 2010).

Family caregiving is an important dimension in dementia care. The issues with dementia are similar to chronic diseases. If we take a chronic disease such as cancer or stroke, there is adjustment that the individual with the chronic disease has to make of themselves due to changing functioning, physical and mental abilities. However, losing these abilities over a longer period of time as for individuals with dementia can lead to a deep sense of grief and loss, in that a person with a diagnosis of dementia knows that their life is going to change radically, they are just not sure when. In a way, individuals lose insight along their journey and gradually lose touch with the familiar parts of their selfhood. The impact and journey for families and significant others as a consequence is often huge.

The dilemma which confronts the person who is providing care is also significant. Taking an example like persons with cancer, their physical well-being will deteriorate but usually their psychosocial abilities remain largely intact (until the very late stage of the condition) so that carers can negotiate the care with them. However, persons with dementia would gradually lose their cognitive and psychosocial abilities, and they may not be able to express about the care and support they need. Also they might lose insight into their impairments and capacity to make sound decisions. So decisions about whether or not they should drive, whether they should go into residential care or spend some time in respite care, and what they would like in terms of

end-of-life care, are left to the person who is the significant other or carer. In these types of situations unfortunately not all families agree with care decisions, and conflicts arise regarding lifestyle choices, and decisions in social, financial and other areas. This places an incredible strain on carers and significant others, at time when carers may not have had responsibility for any of these types of decisions prior in the relationship. It is compounded by the fact that often in society in general, such issues are not always discussed, debated and or resolved openly. When we work with people with dementia, planning ahead is really important, these issues need to be resolved before dementia takes hold.

In relation to the provision of care, this is often left to the carers and families. In some the physical well-being of the person may deteriorate, and provide really quite complex and demanding physical loss of skills. The person with dementia may also need to be able to walk around to lessen their own anxiety (wander) and we need to be able to provide supported places for this to happen safely. As language becomes more difficult, frustrations increase, and ways of expressing need through behaviour become more inappropriate (may become aggressive). It can be difficult for the significant other to manage this person who is different in many ways from the person they loved for this period.

Care in the home, while often seen as desirable both by the person experiencing dementia or the significant other, is often quite difficult to achieve. Some carers have work, and may have children and other family commitments to cope with as well. Providing this type of intensive support can have many negative effects on their emotional, psychological and physical health, social activities and support networks, and ability to work and finances. Some people do not want to provide care but are forced to due to family structure and cultural circumstances,

while other people see it as their duty and part of their vows, or part of their commitment to being a family.

These experiences may also vary across countries. It would be important to conduct cross-cultural research to examine whether that is the case. For example there is an expectation, a belief or a stereotype held that in Asian countries that care is provided at home (Chan, 2010). However, in Australia it is less likely to be provided at home, but there still a conflict for the person making the decision to place the individual in residential care. That dilemma must exist wherever, whichever country we live in and in whichever culture.

End of life care

End of life care is a relative new concept in dementia care. The issues surrounding end-of-life care still remain significant and unresolved. End of life should be underpinned by values of dignity, empowerment, compassion, equity, excellence and accountability. The on going work that the authors are doing suggest that the expectations an individual might have about how they want their end-of-life care to be handled may not in fact be shared with their significant other who may be in the position of making the decision for them. There is evidence suggesting that the agreement between patients' significant others and their healthcare providers is not clear. It remains a taboo subject not clearly enunciated or discussed (Alzheimer's Australia, 2014). It is something that, at least within the Australian context, would need to invest more effort in if we are to improve care. People should be able to share their views about how they want their end of life care to be provided.

It seems simple but actually it is quite difficult. Some people may decide today that they do not want invasive treatment, they want to remain conscious but if pain remains

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too great or difficult, they would rather end their life. But for this to occur it is necessary to take the stigma out of talking about dying, arrange to sit down and talk about it, and have agreement between the patients, the significant others and the care providers. This discussion clearly is not occurring enough within Australian context. This equally applies to people with dementia who need to plan ahead before they lose the capacity and cognitive ability to make the decision. Otherwise it will be made for them by their significant others and that decision may not be what they would have preferred.

It is really important for as many people as possible plan ahead for expected changes and that means putting in place a advanced directive. Between 14 and 20% of people within Australia have advanced directives. But often that is a very crude advanced directive – such as do not resuscitate. When caring for a person with dementia, there are greater subtleties. For example, if the person loses cognitive functioning or efficiency and they get pneumonia, there is a question about whether or not they would want to receive antibiotics in an effort to prolong life even if the event was not life-threatening in itself. We need to find our way in this field about how we can have advanced directive which is appropriate and acceptable for people with dementia and their caregivers. Whatever else we do it is fairly clear that we need to try to find better ways of supporting the person and their family caregiver. We should be seeking to provide them with education, information and guidance about how to plan ahead and ensure that they can make that decision with the person they love before cognitive functioning deteriorates.

Australia Community of Practice in Research in Dementia (ACcORD)

ACcORD is a multidisciplinary team ongoing project in dementia research with \$3.38 million in federal funding ([http://www.](http://www.newcastle.edu.au/highlights/our-researchers/health-medicine/medicine-public-health/the-last-word)

[newcastle.edu.au/highlights/our-researchers/health-medicine/medicine-public-health/the-last-word](http://www.newcastle.edu.au/highlights/our-researchers/health-medicine/medicine-public-health/the-last-word)). This scheme was funded by the federal government in an effort to increase the number of people who are doing research in dementia. The funding was intended to encourage people to shift over to work with people with dementia. In that sense it has been successful. The project included a multidisciplinary team made up of clinicians - both geriatricians and nurses, epidemiologists, statisticians, health economists and health behaviour people as well as a strong representation from consumers. Consumer input is critical for research in this big area. Guidance from people who have experience of this disease and understand the impacts is central to our focus.

The ACcORD project is conducted over a five-year period. There will be 13 separate studies which include projects looking the barriers and enablers to early diagnosis, and whether people want early diagnosis. Dementia is interesting as has distinctive features as compared with other chronic diseases. With other chronic diseases some may suggest that you should only diagnose when early diagnosis makes a difference and you can do something about it. With dementia we know that currently there is no cure and there is no effective treatment. In another area of medicine we would not diagnose if we cannot do anything, but in dementia there is strong community and consumer movement which says if people know that they are getting cognitive impairment then they can make decisions and plan for their future. For example regarding advanced directives, and about legal issues. At present research has been conducted in this area. Such research is intended to improve the quality of care which is provided to people with dementia and the quality of their life. The ACcORD project is not researching into treatment or trying to understand causes or prevention of dementia. This project is trying to do something in the here and now that improves care and people's life situation.

How to improve research in dementia care?

‘How to improve research in dementia care’ is a good but potentially controversial question. Good because researchers should always be trying to think of research that if undertaken would make a difference to the community. It should not be driven by one or two disciplines’ needs and theories. It should be driven by what is good for the community. The money that researchers get for research comes from the community therefore researchers should be returning benefits to the community.

If you ask every discipline this question, they would have a different argument about this. Most people with dementia and their support persons would argue research in dementia care ought to be geared towards a cure or if no cure – prevention. That is laudable and we should. But the question is how much should spend on those things or what proportion of the available resources should spend. If we can get a cure it is not likely to be actualised before somewhere between 10 and 20 years. Prevention is pretty much the same. There are theories about what one should do to prevent dementia, for example, one should exercise or one should eat a Mediterranean diet. There are many different ideas about how one can prevent or delay the onset of dementia. But it is fair to say there is not yet clarity about it, and not yet certainty about it.

What researchers do have to deal with is how to help people cope in the here and now. How can we help them get through the pre-diagnostic and diagnostic process? How do we help them deal with the unmet needs that they may have as a consequence of the diagnosis? The proportion of funding that we should spend should increase in trials designed to improve the quality of life for people with dementia and their support persons. There should be interventions. We need knowledge or evidence that is derived from interventions not from descriptive research. It is not enough

to say there is a problem. We need to seek solutions. We should seek to test interventions using strong methodology to see whether it works. One example is the study on using mobile application to support carers in coping with their caregiving (Chan, Sanson-Fisher, Brummell, Wilson, Hunter, Jeong, Nair & Henskens, 2016). The topic is critical. It is equally critical that the study is subjected to strong and rigorous research methodology so that we know what works. There is no place for strategies that charismatic influential people use to justify an approach without being backed up by research.

Recently the Australian Government has announced the Boosting Dementia Research Initiative in Australia. The idea of trying to increase the number of people who are working in dementia is critical. No one would disagree that we need more people doing high quality research in the field. The debate will be about where researchers would put the effort in. This debate has occurred in chronic diseases, such as stroke and cancer. National Health and Medical Research Council is the major research funder in Australia. It allocates approximately 58% of its money to basic science research. Again, we would not debate that it is not important. Whether or not there should be more research allocated to try to help people cope with the disease is also critical.

To enhance the quality of dementia care, it is very important to undertake collaborative cross-cultural research. Australian researchers are very keen to explore research opportunities with researchers and clinicians in Hong Kong and readers of the Hong Kong Mental Health Journal. We can learn a lot from the ways in which different cultures and different societies cope with dementia. For example, there are ongoing studies with Japanese colleagues on dementia care, and with nursing colleagues in Hong Kong to examine nurses’ perceptions about what we should be doing in this field. It is important to reach out to people with dementia and their carers in whatever country.

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We can compare findings from other countries with Australia. If we find differences it tells us something that is really very important. The influence of culture on the care that is provided, and the resources which allow improvement of care in relative countries.

Conclusion

This paper shares with readers on critical issues and debates in Australia related to dementia care and research. It is important that we learn from each other's experience. International collaborative cross-cultural research studies can help to generate global solutions to improve the lives of people living with dementia and their families.

摘要

澳洲的認知障礙症照顧 - 政策、實踐及研究

認知障礙症預計將成為全球第四大主要負擔的疾病及澳洲第二大死亡原因（澳洲統計局，2016）。本文報告了澳洲紐卡素大學Professor Robert Sanson-Fisher的訪問。訪問目的是與讀者分享澳洲對認知障礙症照顧的政策、實踐和研究。本文強調澳洲於國家框架下有關對認知障礙症行動的主要原則、以患者為中心的照顧概念、家庭和支援人員的歷程、臨終照顧以及對認知障礙症照顧的研究發展。對於創造全球解決方案以改善患者及其家庭的生活，國際及跨專科的合作不可或缺。

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