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Introduction

The increasing prevalence of dementia around the globe mandates that healthcare workers have a solid understanding of the complexities of dementia care, particularly in a practical context. Contemporary healthcare is person-centred, with the recipients of care and their support network at the centre of care planning and health management. Therefore, lived experiences and personal narratives are rich sources of knowledge that can inform how health professionals approach their work.

Ed’s Story is one of those lived experience narratives – it is Ed’s journal that describes his world as he cares for Mary, diagnosed with Lewy Body Dementia. This chronicle brings a sense of reality to discussions about care provision for dementia sufferers and provides valuable insight into the world that carers are thrust into upon diagnosis.

Further, Ed’s Story provides a foundation for better understanding the world of a carer and how service provision impacts on the health outcomes for the patient and those around them (Nicholson, 2009). This suite of electronic resources is designed to provide learning experiences for health science students that they can draw on as foundation knowledge for practice.
Background

As dementia typically affects older adults, the concept of caring for dementia sufferers in the community is related to two key features of the current global and Australian population: an ageing population and an increase in the number of diagnosed cases of dementia.

An ageing population is reflective of good standards of care across the lifespan. That is, to reach old age is an indicator of how healthy a person has been throughout their life. There are, however, physiological changes that occur as a person ages. These are normal changes of ageing that predispose older adults to chronic illnesses that can challenge their health and well-being. For these reasons, older adults comprise a large portion of the consumers of healthcare. Other risk factors of chronic disease for older adults include demography, behaviour, biomedical factors, genetics, environment, social or comorbidity factors (Bramble, 2014).

In Australia, ageing in the Aboriginal and Torres Strait Islander peoples must be given special consideration, particularly in the context of the ‘Closing the Gap’ initiative. Currently, the life expectancy of Aboriginal and Torres Strait Islander people is around 17 years less than the non-Indigenous population in Australia and the Closing the Gap initiative aims to reduce the gap in life expectancy. The social determinants of health impact significantly on the quality of life for our Indigenous people and are a key factor for poorer health outcomes and chronic disease rates for this population group. For example, Aboriginal and Torres Strait Islander people have higher rates of diabetes, hypertension, cardiovascular disease, and chronic renal disease than the non-Indigenous
population (AIHW, 2015). Dementia incidence for Aboriginal and Torres Strait Islander people is also believed to be higher than the national average (Qin Li et al., 2014), despite suspected low diagnosis and reporting rates. Further, the age of onset of dementia in Aboriginal and Torres Strait Islander people is lower. Figures from the AIHW (2015) reporting on Indigenous people in residential aged care facilities show:

- 51% of Indigenous residents had a diagnosis of dementia (similar to the 52% of non-Indigenous residents)
- 26% of Indigenous residents aged 55 years and under had dementia
- 61% of Indigenous residents aged 75 years and over had dementia

(AIHW, 2015, p. 123)

Recognition of the health disparities for Aboriginal and Torres Strait Islander people requires health professionals to consider culture as a measure of ageing. That is, ageing is more than chronological ageing. Rather, ageing is a multidimensional concept.

An holistic approach to the concept of ageing underpins the principles and frameworks for care of older adults. Consideration is given to the influences on how people age such as chronology (years), biology, physiology, biomedicine, psychology, social and cultural values and beliefs, and economic and spiritual influences. For this reason, among others, it is important that all health professionals consider ageing as a multidimensional concept as well as considering individual persons.

Although the incidence of older adults accessing healthcare is referred to throughout this text, the intent is to merely present that as statement of fact.
This is not, as warned by Duckett (2016), evidence of support for the “apocalyptic argument” (p. 212), the “silver tsunami” or subscribing to the concept of “voodoo demographics” (p. 212). However, it is important to consider the entry of the Baby Boomers into the realms of older adulthood that began in 2011. Baby Boomers are those members of the population born between 1946 and 1964 and represent the biggest single increase into older adult numbers ever. As well as the increase in numbers of people requiring access to services due to age related health changes, there are features of the Baby Boomer cohort that will influence or frame how care is provided. Baby Boomers are expected to have higher expectations than previous generations, based on a greater proportion of the cohort having previously higher incomes, higher education levels and higher paying and influential employment prior to retirement (Bramble, 2014). Therefore, recognition of all of the factors that influence care provision and health outcomes is imperative to understanding the world view of the older adults and their carers.

Healthcare is one of the largest expenditures for any government, and as the population ages, with the associated increase risks of chronic disease and co-morbidities, it is expected that there is an associated increase in the cost of healthcare provision. For this reason, governments and policy makers around the world have prioritised healthy ageing and aged care service provision, promoting an ageing in place philosophy (Brown & Bond, 2016).

To better understand the extent to which the government funds aged care, a comprehensive list of aged care services funded by the Australian Government is publically available at:
Reference to this list does not imply that these authors necessarily agree with the distribution of funds or funding models. It does, however, allow the reader to see how far and to what degree funding is distributed.

Dementia

Dementia is recognised as a global challenge with over 7 million new diagnoses annually worldwide (Svendsboe et al., 2016), and is one of the Australian government’s identified health priority areas (Australian Institute of Health and Welfare [AIHW], 2012). This means that considerable resources for disease management, service provision and education have received federal funding in order to improve the quality of life outcomes and thereby the cost of dementia as a burden of disease.

There are numerous types of dementia that, grouped together, make up one of the leading causes of death in older adults and burden of disease in Australia (AIHW, 2015). The current and predicted impact of dementia prompted the Australian federal government to declare dementia a national health priority in 2012. The following table illustrates the most common types of dementia.

Table 1: Types of dementia (Source: Moyle, 2014, p. 94)
<table>
<thead>
<tr>
<th>TYPE OF DEMENTIA</th>
<th>CHARACTERISTICS</th>
<th>SYMPTOMS</th>
<th>BRAIN CHANGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease (AD)</td>
<td>• Most common &lt;br&gt; • Accounts for 60-70% of dementia cases &lt;br&gt; • Progressive degenerative disease &lt;br&gt; • Almost all people with Down syndrome will develop AD</td>
<td>Early symptoms: Difficulty remembering names and recent events; apathy and depression. Late symptoms: Impaired judgment; Disorientation; confusion; behaviour changes; difficulties with speech, swallowing and walking</td>
<td>Deposits of beta-amyloid (plaques) and tau (tangles) as well as evidence of nerve cell damage and death in the brain</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>Second most common form of dementia &lt;br&gt; Can be mixed dementia</td>
<td>Early symptoms: Impaired judgment; inability to plan to complete a task</td>
<td>Brain injury as a result of bleeding and blood vessel blockage</td>
</tr>
<tr>
<td>Dementia with Lewy bodies (DLB)</td>
<td>Early symptoms: sleep disturbance; visual hallucinations; muscle rigidity; large fluctuations in attention and thinking</td>
<td>Abnormal clumps of the protein alpha-synuclein</td>
<td></td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>Early symptoms: problems with movement; dementia symptoms are similar to DLB</td>
<td>Abnormal clumps of the protein alpha-synuclein in the substantia nigra. Thought to cause degeneration of the nerve cells that produce dopamine.</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal dementia (Pick's disease)</td>
<td>Usually develops at a younger age, around 60</td>
<td>Changes in personality and behaviour; language difficulties; difficulty recognising objects, understanding or expressing language</td>
<td>Involves degeneration in one or both of the frontal or temporal lobes of the brain</td>
</tr>
<tr>
<td>Wenicke-Korsakoff syndrome</td>
<td>Chronic memory disorder caused by severe deficiency of thiamine; usually caused by alcohol abuse and is irreversible</td>
<td>Memory problems; personality changes; visual and auditory hallucinations; lack of insight</td>
<td>When thiamine levels fall too low, brain cells do not function</td>
</tr>
</tbody>
</table>

According to the AIHW (2015), the disease incidence of dementia is expected to increase threefold in the coming decades to around 900 000 in 2050. These predictions mandate that serious consideration is given now to models of care and strategies for service provision that promote quality of life for
individuals, families and communities, minimise the demands on the health system, and are cost effective and sustainable.

In 2011, the AIHW estimate the prevalence of dementia by severity as just under 164,000 people with mild dementia, nearly 90,000 people with moderate dementia and around 50,000 people with severe dementia. The following table shows the predicted number of dementia cases in Australia, based on current figures and trends (AIHW, 2016).

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people diagnosed with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>342,800 (actual)</td>
</tr>
<tr>
<td>2020</td>
<td>400,000 (predicted)</td>
</tr>
<tr>
<td>2050</td>
<td>900,000 (predicted)</td>
</tr>
</tbody>
</table>

Table 2: Dementia diagnoses by number in Australia (AIHW, 2016).

Statistically, dementia affects around one in ten people over the age of 65, and three in ten over the age of 85 (AIHW, 2015). These statistics are evidence of the prevalence of dementia diagnoses in our communities, and when they are considered in the context of at least one in ten families/friendship groups are affected by a dementia diagnosis, the importance of quality, appropriate and relevant health care is apparent.

While statistics for dementia are grouped together, current research such as that by Svendsboe et al (2016) shows that there are notable differences into
the effects on caregivers between different types of dementia (Nicholson, 2009). For example, these authors found that caregivers for people with Lewy body dementia report different types and manifestations of stress than caregivers for people with Alzheimer’s dementia.

WHERE ARE THEY?

Currently 50% of residents in residential aged care facilities have dementia and one in three people with severe dementia live in the community. Dementia sufferers living in the community require round the clock care. These figures, combined with the incidence statistics highlight how dementia impacts on our communities.

Accordingly the provision of care must recognise the needs of the person, their family, and the community, adding value to the need for healthcare workers in all disciplines to have a solid understanding of dementia care and their role in the healthcare team. The cost of long term service provision, including workforce implications, has resulted in initiatives to promote dementia sufferers staying at home, with appropriate support, for as long as possible. Recently, the Australian government has implemented numerous packages that dementia sufferers can access to remain living at home.

MODELS OF CARE

There are numerous models of care implemented around the world that reflect current best practice with the aim of providing the best possible
CAPABILITIES MODEL OF DEMENTIA CARE

Models of care vary between organisations and locations. Moyle’s Capabilities Model of Dementia Care (CMDC) (Bramble, 2014) is one model of care that frames dementia care provision, particularly in relation to residential aged care provision. These same principles can be applied to dementia care in acute healthcare facilities and community setting. Key to the CMDC are 10 capabilities that are considered “fundamental opportunities” (Bramble, 2014, p.39). These 10 capabilities are:

1. Feel valued
2. Experience the best health possible
3. Live independently with compassionate support from important others
4. Enjoy pleasurable experiences through senses, imagination and thought
5. Experience and express emotion in a way that is true to oneself
6. Reflect and decide on things that matter to oneself including plans for the future and end of life
7. Experience connection with others where they can contribute and be contributed to and where there is self-respect, dignity and a sense of shared humanity with individuals and the wider community
8. Live in a way where engaging with nature (plants, animals, sun, moon) is a natural part of life
9. Play in a way that is meaningful and fun
10. Experience a sense of control in how to live their life

(Bramble, 2014, pp. 39-40)

COMMUNITY CARE PACKAGES

In recent decades, there has been a strategic move to shift long term care for dementia sufferers to the community, away from residential care. Changes to
community service provision are ongoing, with funding frameworks evolving to suit consumer demand. Previous to 2015, eligible recipients of care packages were entitled to a range of services provided within a rigid framework. In 2015, the way in which funding is provided for community care was amended to give the patient, and their support networks the ability to build a care package that is individualised and tailored to suit their needs. This frames what the government has termed “consumer directed care” (REF). Consumer directed care places the patient and their carers at the centre of care planning, as is consistent with the person-centred philosophy of contemporary healthcare.

AUSTRALIAN LEGISLATION

There are legislated guidelines for the provision of aged care in Australia within which services are provided. The legal parameters are defined by the Aged Care Act, the Aged Care (Transitional Provisions) Act 1997, the Aged Care (Accommodation Payment Security) Act 2006, and the Aged Care (Accommodation Payment Security) Levy Act 2006. These Acts are supported by a number of legislative instruments made under the Aged Care Act and the Transitional Provisions Act. In addition the Australian Aged Care Quality Agency Act 2013 sets out the functions of the Australian Aged Care Quality Agency (http://guides.dss.gov.au/guide-aged-care-law).

The objectives outlined in the Aged Care Act are:

- promoting high quality care and accommodation,
- protecting the health and well-being of care recipients,
helping recipients of aged care enjoy the same rights as all other people in Australia,
ensuring that aged care is accessible and affordable for people who require it,
planning effectively for the delivery of aged care services,
ensuring that aged care services and funding are targeted towards people and areas with the greatest need,
encouraging services that are diverse, flexible and responsive to individual needs,
providing funding that takes account of the quality, type and level of care,
providing respite for families and others who care for older people, and
promoting 'ageing in place' - that is, helping older people stay where they want to live, by linking care and support services.

Within the current legislation, the government is committed to providing financial support in the form of subsidies and grants; overseeing the approval of payments to providers; regulate fees; and ensure providers fulfil their responsibilities within the Act (http://guides.dss.gov.au/guide-aged-care-law).

Current and potential recipients of aged care services in Australia can build an individualised Aged Care Package via the 'My Aged Care' website, available at http://www.myagedcare.gov.au/, with further information for carers available at http://www.myagedcare.gov.au/caring-someone. The opportunity to build a personalised aged care package is a reasonably new initiative, in response to
demand from both consumers and care providers. However, consider for a moment, the age group most likely to require these services. While many older adults work well on electronic media, there is a proportion of this age group who are not familiar with online activities. There are options for those who do not have, or unfamiliar with, the internet, but these options are not actively encouraged. Thus, there is the potential for the older adults who are not familiar with working online to face barriers, or even exclusion, to accessing services.

Providing care for dementia sufferers in the community is more than the Aged Care Packages outlined above. It relies heavily on informal carers who are family or friends who provide care and support for loved ones. The role of carers is far more complex than it initially appears. In addition to learning about the disease processes, and navigating a complex health system, there are considerable personal changes they undergo. There are relationship and role changes within the relationship with the person with dementia, with subsequent changes in family dynamics and family relationships.

**CARERS – THE INFORMAL WORKFORCE**

A carer is a family/friend/community member, usually known to the person, who provides some form of supportive care that enables the person to remain in their own home. Informal carers are not usually paid for their services and in many cases do not have a professional background in healthcare. There are also cultural implications for informal carers. In some cultures, caring for older adults across generations is expected and accepted as a normal family function. In other cultures, it is not as accepted as part of family responsibilities.
These factors must be taken into consideration when discussing the role of carers and their experiences, particularly when planning care as part of a healthcare team.

Caregiver strain or burden has been contextualised in several ways, but, according to Leggett, Zarit, Taylor and Galvin (2011), can generally fit in the dimensions of role strain and personal strain, although their research showed a third category of worry about performance. Caregivers report that dealing with behavioural changes and emotional challenges are two of the most stressful factors in caring for someone with dementia, particularly Lewy body dementia (Leggett et al., 2011). These authors also found that being an older caregiver was generally linked to increased role strain while being a younger caregiver was linked to worry about performance. This is interesting because in many cases, the spouse is the primary carer for someone with Lewy body dementia. Therefore, it is important to be cognisant of the carer’s predisposition to feeling the pressures of role strain. Adult child caregivers also report higher levels or carer distress, which is important to consider when reading Ed’s Story, as his daughter Marie became Mary’s fulltime carer for several years. Although Marie coped quite well, when you read her poem about caring for her mother, the pressures she felt are apparent.

The physical, psychological and emotional pressures faced by informal carers that can manifest in different ways. For example, approximately 1 in 3 informal carers reported fatigue related symptoms and 1 in 3 reported feeling worried/depressed as demonstrated in the following tables.
Adverse effects due to caring role

<table>
<thead>
<tr>
<th></th>
<th>Primary carers of people with dementia</th>
<th>All primary carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel weary or lack of energy</td>
<td>34.3</td>
<td>32.9</td>
</tr>
<tr>
<td>Frequently feel worried or depressed</td>
<td>33.2</td>
<td>30.1</td>
</tr>
<tr>
<td>Diagnosed with stress-related illness</td>
<td>10.3</td>
<td>11.3</td>
</tr>
<tr>
<td>Frequently feel angry or resentful</td>
<td>14.7</td>
<td>12.1</td>
</tr>
<tr>
<td>Not stated</td>
<td>7.9</td>
<td>10.0</td>
</tr>
<tr>
<td>One or more of the above adverse effects</td>
<td>57.2</td>
<td>48.2</td>
</tr>
</tbody>
</table>

Table 1: The adverse effects of caring (AIHW, 2015)

Table 1 clearly illustrates that at least half of all primary carers of people with dementia report some adverse effects. In some areas, primary carers of people with dementia report have reported more adverse effects than primary carers in general. It is unstated but may be reasonable to assume that the adverse effects described in Table 1 may well be manifestations of role strain or personal strain. Further, the worry reported by carers may include some worry about performance as described by Leggett et al. (2011).

Sleep disturbance due to caring role

<table>
<thead>
<tr>
<th></th>
<th>Primary carers of people with dementia</th>
<th>All primary carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep interrupted frequently</td>
<td>34.0</td>
<td>24.2</td>
</tr>
<tr>
<td>Sleep interrupted occasionally</td>
<td>32.4</td>
<td>24.4</td>
</tr>
<tr>
<td>Sleep not interrupted</td>
<td>26.6</td>
<td>42.0</td>
</tr>
<tr>
<td>Other</td>
<td>7.0</td>
<td>9.4</td>
</tr>
</tbody>
</table>

Table 2: Carer’s sleep disturbances (AIHW, 2015)
Table 2 shows that carers for people with dementia report greater disturbance to sleep patterns. This information, taken in context, provides insight into the strain of caregiving on the carer. Lack of sleep can in turn predispose the carer to mental and physical fatigue and even exacerbation of their own health challenges. Lack of sleep can also affect their emotional state and mood which has the potential to translate into anger and frustration with the person for whom they are providing care. While this may not place the recipient of care at increased risk of abuse or neglect, it may well change the dynamics of the relationship between family members and/or friends, fracturing the very important support network for both the person with dementia and their carer.

<table>
<thead>
<tr>
<th>Satisfaction due to caring role</th>
<th>Primary carers of people with dementia</th>
<th>All primary carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feels satisfied</td>
<td>18.7</td>
<td>20.9</td>
</tr>
<tr>
<td>Does not feel satisfied</td>
<td>73.4</td>
<td>69.1</td>
</tr>
<tr>
<td>7.9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Carer's self-reported satisfaction with the caring role

The data in Table 3 shows that very few carers gain satisfaction, let alone fulfilment, from the carer role.

The combined data in Tables 1 to 3 highlight the effect of caregiving on the carer under the broad umbrella term of dementia. However, as previously stated, the specific symptoms of Lewy body dementia have been identified as most likely to trigger caregiver burden (Nicholson, 2009).
The statistics in the above tables show the impact that informal caring can have on anyone, regardless of age, health status and background (Brown & Bond, 2016). However, consider for a moment that frequently informal carers for older adults with dementia are their spouses. That is, they too are older adults, in many cases with their own health concerns. As previously pointed out, lack of sleep and stress can exacerbate underlying medical conditions. When added to the normal physiological changes of ageing which can alter physical and mental endurance, the possible implications are concerning.

The take home message from this section is that as healthcare professionals and policy makers, we need to remain mindful of whom is shouldering the responsibility for day to day care of people with dementia in the community. That is, consider what we are asking and of whom. Informal care provision relies on emotional ties and a sense of obligation and commitment that should not be undervalued. Despite the best of intentions in the long run it may have a profound detrimental effect on the health and wellbeing of more than one older
adult, and thereby create another level of complexity to the existing challenges of an ageing population in the community.

WORKFORCE IMPLICATIONS
The previous discussion highlighted the impact of informal caring on the caregivers. There are also significant workforce implications associated with decision making about informal caregivers. There are effects on the health workforce and the roles they play as well as the effect on workforces generally when members of the workforce provide care for a community member of loved one outside their paid duties.

The role of informal caregivers influences decision making and policy development about care provision which in turn decides formal workforce planning for dementia care. For example, if an informal caregiver is providing much of the day to day care, the frequency of visits from healthcare professionals, in particular, nurses, is reduced. The carer often attends to the daily tasks of personal hygiene and meals and the nurse attends to wound care and medications. This means that more visits to more people may be allocated to each nurse and the workload is distributed accordingly.

There are predicted health discipline workforce shortfalls over the coming decades that add further urgency and importance to the provision of care in the community for dementia sufferers. The ageing population and the predicted increase in dementia diagnosis combined with the predicted workforce shortfalls and the burgeoning costs of health care mean that alternatives ways of providing care, including the use of informal carers must be considered. Therefore it is also
imperative that the role of carers, often older adults with complex comorbidities themselves, is considered and incorporated into health care planning. It is also important that health professionals in all areas, at all levels, include informal carers as part of holistic health assessment and care planning.

AIHW estimates – 2011, approx. 200 000 informal carers in the community
Those informal carers who live with the person with dementia are most likely to provide >40 hours of care per week.

While the strain of caregiving is well documented, particularly in the context of caregiver burden, there is also some evidence about what happens to the caregiver after their caring role is finished. When the person for whom they have been providing care dies or is moved to residential care, what effects stay with the carer and how long term are these effects? Brown and Bond (2016) report that there is very little difference in the effects on the caregiver in relation to the cause of separation. That is, whether the caregiver role finishes due to death or permanent relocation to residential aged care facility, the effects on the caregiver are similar. However, it is also prudent to remember that even in the best of circumstances the carer will have aged since they began their caring role. Thus in addition to their altered physical capacity brought on by the caring role, the normal physiological changes of ageing may be more apparent. Research conducted by McConaghy and Caltabiano (2005) supported the current body of evidence but added new knowledge that depression did not contribute to the carers’ perception of wellbeing.
REFERENCES


