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Inquiry into Dementia: Early diagnosis and Intervention.

MAC.ART

McADAM AGED CARE ART RECREATION THERAPY

This submission is made by

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Inquiry into Dementia: Early diagnosis and Intervention.

Terms of reference

The committee will inquire into and report on dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- Improve quality of life and assist people with dementia to remain independent for as long as possible
- Increase opportunities for continued social engagement and community participation for people with dementia
- Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and prepare for long-term or more intensive care requirements; and
- How best to deliver awareness and communication on dementia and dementia related services into the community.

ABOUT THE AUTHOR

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Dr Gross McAdam holds undergraduate and postgraduate qualifications in the graphic arts, aged care, dementia services and palliative care. These qualifications include a Graduate Certificate in Aged Services, a Graduate Diploma in Dementia Care and Service, and a Master of Health Science – Aged Services degree. Her PhD thesis was on the relationship between art and wellbeing for those living with dementia.

Glossary of keywords

Alzheimer's disease: The most common form of dementia 'discovered' by Alois Alzheimer in 1906.

Biomedical model: A mechanical/reductionist approach to healthcare that tends to place the treatment of the disease, rather than the person, at the centre of the care equation.

Care partner/s: A dementia/disability term increasingly used to replace the term 'caregivers'. They are individuals who share the care responsibilities of individuals living with dementia in, it is assumed, a reciprocal and equal way.

Creative expressive arts therapies: A term used to describe a group of therapies that may include, but not limited to, art, music, poetry, reminiscence and dance and movement.

Dementia: An umbrella term to describe the eighty or more diseases or syndromes that result in progressive cognitive impairment.

Kitwoodian theory: The theoretical/philosophical ideas that are based on the dementia-specific writings and model of care designed by the late Professor Thomas Kitwood (1937-1998), an English academic specialist in dementia care.

Living with dementia: A dementia/disability term that has since the 1990s increasingly replaced the biomedical term "suffering from dementia".

Old culture of care: A term coined by Kitwood to describe a biomedical worldview and approach to dementia care.

Person-centred care and model: A model of care designed by Kitwood that places the person and their needs at the centre of the care equation.

Psychosocial interventions: A term to describe a group of psychological and social (psychosocial) non-drug interventions, such as art, music, dance and movement, pet and horticultural therapy used in aged care to advance the quality of the lived experience of individuals with dementia.

Executive Summary

The aim of the House Standing Committee on Health and Ageing is to inquire into the early diagnosis of dementia and how interventions can improve quality of life, promote independence, increase opportunities for social engagement and better prepare those living with dementia, and their care partners, for the challenges of long-term care.

To assist the Committee in this goal, this submission advocates from a person-centred care perspective. It actively promotes the wider recognition and introduction of dementia-specific, psychosocial interventions, including the creative expressive arts therapies across Australian society.

To further assist the Committee, this submission cites current international reports and identifies best practice programming, aimed directly at increasing the wellbeing and quality of life of those living with dementia, and their care partners, that have been tried and tested in North America and Britain. This submission's main recommendation is the development of a "stock resource" of existing psychosocial interventions for future use. In addition, to meet future anticipated demand, it advocates fuller recognition and support for a more pro-active development of such resources.

This submission argues that dementia is still something of a "taboo" subject in Australia, and it presents evidence that suggests that dementia is poorly understood in the wider community. These issues are addressed when this submission recommends the Australia-wide adoption and introduction of positive dementia-specific terminology, beginning with the term "living with dementia".

The author directs the Committee to current international dementia-specific research on wellbeing and quality of life that indicates that most individuals living with dementia are capable of making advanced care planning decisions at the time of diagnosis and for sometime afterwards. Research demonstrates that individuals living with dementia worldwide share the same needs, aspirations and fears for old age as most Australians. To this end, this submission strongly recommends that the Committee take note of the international experience in its deliberations.

The author of this submission asks that the voice of Australians living with dementia and their care partners be heard. And, for all those who advocate for the wider introduction of psychosocial interventions, noted throughout this submission, it is hoped that their ideas and recommendations may be of use to the Committee in its deliberations.

Introduction

"What is the difference between Alzheimer's disease and dementia?" is the most common question that I have been asked during the past decade working in residential aged care in Australia. There is widespread confusion about dementia in Australia, and little appreciation that dementia is an umbrella term to describe more than eighty different diseases, syndromes and illnesses that result in progressive cognitive impairment. Dementia takes many different forms. A single cause is still unknown. While there are many similarities among the many forms, experience and the progression of dementia is unique to each person. Any approach that sets out to improve the quality of life and wellbeing of those living with dementia must begin by recognizing the centrality of this truth.

There is another very important aspect of dementia that is still little appreciated. It relates to the increasing evidence that psychosocial interventions, including the creative expressive arts therapies, can have a significant positive effect on the emotional health and wellbeing of those living with dementia and their care partners. Since the beginning of the last decade before the dawn of the new millennium, a steadily growing group of healthcare professionals around the world, with North American and British dementia care specialists in the lead, have advocated with ever greater persuasiveness the benefits of psychosocial interventions known to increase quality of life in those living with dementia (Allan, 2003; Allan and Killick, 2002; Basting & Killick, 2003; Camp *et al*, 2002; Cody *et al*, 2002; Cohen, 1995 & 2000; Cohen-Mansfield, 2001; Gottlieb-Tanaka, 2004, 2006 & 2006a; Killick and Allen, 1999, 1999a, 2001 2011 & 2011a; Killick, 2000, 2003, & 2010; Koenig-Costa, 2004; Kolanovski *et al,* 2006; Kovack *et al,* 2005; Levine Madori, 2007; McFadden, 2005, McFadden *et al,* 2008, McFadden & Lunsmen, 2009; Raia & Koenig-Costa, 1996; Rylatt, 2012; Teri *et al,* 2002; Verity & Kuhn, 2007; Whitehouse and George, 2008 & Zeisel *et al*, 2003; Zeisel & Raia, 2002).

In 2006, select members of this group gathered at the UWM Centre on Age and Community (University of Wisconsin, Milwaukee campus) to formulate strategies to broaden the research scope and implementation of psychosocial interventions in dementia care. The final delegates' report (Bernfeld & Fritsch, 2006) concluded that person-centred care is the core element necessary for both optimal humane care and cultural change in this sphere. The unanimous finding of the delegates asserts that "creative-expressive programs have very few side effects, and have real potential to benefit" those living with dementia now and in the future (Bernfeld & Fritsch, 2006, p. 12).

The value and suitability of dementia-specific psychosocial interventions has been overlooked for too long, a circumstance too often compounded by media superficiality that focuses on supposed medical breakthroughs in dementia. It cannot be overstated that this emphasis on breakthroughs raises unrealistic expectations in the public mind, and the hopes of those living with dementia and their care partners.

The key unanswered mystery of Alzheimer's disease

The truth of the matter is that scientists still cannot explain why certain cells in the brain embark on a course that damages the brain whilst others, when damaged by a stroke for example, enable the brain to make a full recovery. Why abnormal proteins have such a devastating affect on some individuals, whilst laying dormant and sparing others, is unknown and remains the key unanswered mystery of Alzheimer's disease (AD). Non-psychosocial drug treatments currently available to treat AD cannot stop the progress of dementia and almost invariably tend to be only effective for a very limited period of time. While they can perform a memory enhancing function in the short term, it is well documented they also can have serious side effects in some individuals (Shenk, 2003).

Speaking at a symposium on the advancement of the understanding of dementia in July 2011, the Baroness Greenfield, Professor of Pharmacology at Oxford and one of the world's leading scientific experts in AD research, made the following observation: the general public is under the misconception that the world's scientists are working on the "cure" for AD, but until the cause of AD is identified and fully understood no steps can be taken to develop a cure. She argues that time is of the essence. For even if the cause of AD was identified today, it could still be at least a decade before non-psychosocial drug therapies, to effectively treat and/or cure the disease, would become available to those affected. And, whilst in the future some non-psychosocial drug therapies may well stop the progress of AD in some individuals, nothing can replace dead brain cells and synaptic connections or repair the damage to the brain that has already taken hold.

If Greenfield is correct in her timeline estimations then a "cure" for AD will come too late for a significant number of the baby-boomer generation, in Australia alone we could be talking about three quarters of a million people. We must harness the power of psychosocial interventions if we are to offer care partners, who will ultimately carry the financial and emotional burden of care for those affected, realistic options and real choices. It is already too late to continue to rely on speculative expectation of some biomedical breakthrough and "silver bullet" cure.

The Baroness Greenfield made two simple but seminal recommendations; Firstly, "we must abandon the traditional dogma that there is only one approach [to dementia research]"; and, secondly, as she counselled delegates, "when at a crossroad, and you can take many paths, take them all" (Greenfield, 2011).

Living a fulfilled life

There is little doubt that most Australians, if given the chance to make a choice, at the time of diagnosis, would rather choose to go on "living with dementia”, with some element of dignity and comfort, rather than live an unfulfilled life “suffering from” it. The one research path I propose would at least lead to a better appreciation and understanding of the impact that psychosocial interventions have on wellbeing. At a time when there is no “cure” for dementia on the horizon, a wider acknowledgement and acceptance of the many psychosocial interventions that already exist, specifically designed to address the wellbeing and quality of life of individuals with dementia, is long overdue. At the very least, it offers Australians and others around the world some ray of hope, and some comfort.

Whilst nations such as England and the Netherlands would appear to lead the way in Europe (Alzheimer’s Australia, 2011), Australia, with its relatively small population, has a unique opportunity to lead the world in the nationwide adoption and implementation of best practice dementia-specific, person-centred care.

Dementia as a "human rights" issue

2011 marked the year the first of the baby boomer generation turned sixty-five. This generation has a particularly significant role to play in Australia and in the world's future. Collectively, the baby-boomers will consume more resources, demand more choice and expect society to have a greater understanding and acceptance of what contributes to the quality of life of those living with dementia (Vann, 2010). And, if dementia is not adequately addressed, the baby-boomer generation might well ensure that their plight becomes a significant human rights issue (Zeisel, 2010). Although it may not as yet be fully recognized, both early diagnosis and the creation of choice in care options will be increasingly expected and ever more demanded.

Dr Anne Davis Basting was born in 1965 and, as founder and director of the University of Wisconsin Centre for Aging and Community, she represents the first of a new era of young and articulate international 'dementia as disability' advocates. Basting, in her book *Forget Memory* (2009, p. 159), writes that she is certain that the early diagnosis of dementia in a growing number of baby-boomers will see "a joining of the disability rights and dementia advocacy movement". Basting points out that dementia advocacy is unlike the disability awareness movement of the past. She concedes "the disability rights movement's focus on independence is clearly not at the core of dementia advocacy". Rather, she challenges those who advocate for the rights and independence of individuals with disabilities to fully consider the complex and interdependent relationship that those living with dementia have with their formal and informal care partners. Basting believes care partners, and particularly dementia advocates from the baby-boomer generation, one increasingly affected by dementia, have an important role to play by demanding greater access to person-centred psychosocial interventions when considering their future care options. Basting believes that such a coalition will insist on a wider range and variety of resources, treatments and assistance and this, in turn, will create cultural change and a more realistic awareness of dementia.

Dementia, wellbeing and quality of life. What we can learn from the British experience.

To address the terms of reference of the Standing Committee and begin to develop a new approach to meet the challenges of providing a level of support the baby-boomer generation will demand, it is important to clarify what such phrases as “quality of life” and “individual wellbeing” mean to those living with dementia and their care partners. Early diagnosis of dementia is all very well, but psychosocial interventions and programs must continue to be developed to fill the void created by the absence of psychosocial services in contemporary Australia.

Vernon (2008, p. 44-45) notes that “wellbeing is a useful term because it is relatively unfamiliar”. He adds, “*The Oxford Dictionary of Quotations* has dozens of entries for happiness and happy [but] there is not a single one for wellbeing”. Even the dictionary editors are not clear how to spell the word, for they ask, “Is it wellbeing or well-being?” Vernon points out that wellbeing “embraces notions of health, contentment and flourishing, it includes psychological growth as well as physical welfare [and] it has an individual and community aspect”. Vernon believes the concept is so elusive that “our wellbeing depends in some way on that which is beyond us”, and for most people the concept is “by definition in large part unfamiliar, unusual and unknown. It emerges as something shown or revealed, not told or made. It is an experience not a rule; although informed by reason it outstrips rationality” (Vernon, 2008, p. 12). While much of our media links wellbeing with wealth and body image, the notion of wellbeing expands well beyond such glossy considerations. Vernon believes wellbeing is based on meaning; he writes, “pleasure matters [but] meaning matters more and the transcendent good underpins it” (Vernon, 2008, p. 99).

Recently, individuals living with dementia in the United Kingdom were asked to evaluate and comment on their personal wellbeing and lived experience. The results have been published by the Alzheimer’s Society UK (AS UK) in a

2010 research project report entitled *“My Name Is Not Dementia”: People with dementia discuss quality of life indicators* (Alzheimer’s Society, 2010), and in the accompanying *My Name Is Not Dementia: Literature Review* (Alzheimer’s Society, 2010a). These reports fully explore the concepts of wellbeing and lived experience as they relate to individuals living with dementia. Indeed, they have the distinction of being the first and most comprehensive research initiative of its kind in the world. The AS UK report, we are informed, is the result of a project “carried out in 2009 and early 2010” and is a follow up in an earlier publication *“Dementia Out of the Shadows”* (Alzheimer’s Society, 2008). Australian policy and decision-makers can learn much from their findings.

Sharing the same needs and experiences

Research shows that once an individual is diagnosed with dementia “all too quickly [the disease is] perceived [by society] to be the all-consuming feature of a person’s identity” (Alzheimer’s Society, 2010, p. 45). In truth, individuals living with dementia “remain complex and multi-faceted and their quality of life is no less complex” than anyone else’s (Alzheimer’s Society, 2010, p. 45); indeed, many share the same psychological needs and social experiences, and many of the same fears and aspirations as everyone else. In fact, the top ten wellbeing indicators are “similar, or even the same” as those shared by the general population (Alzheimer’s Society, 2010a, p. 23). Some two decades ago, the Alzheimer’s Society of Canada encapsulated the basic psychosocial needs of those living with dementia when it published the following guidelines:

> In addition to physical needs such as the need for security, nutrition and good health, people with Alzheimer’s disease have the same psychosocial needs as other individuals. They need stimulation and companionship, they need to feel secure, to feel they are unique and valued individuals, and so feel a sense of self-esteem (Alzheimer’s Society of Canada, 1992, p, 3).

The key wellbeing indicators and priorities identified by the UK research participants in 2010 are little different. In order of importance, the UK participants' indicated that their wellbeing is anchored by the hope of good health and companionship, the pleasure of close and sharing relationships, the comfort and reassurance of a friendly voice and human touch, all within a safe, secure, and emotionally supportive environment. In short, a lived experience that has meaning, encompassing what Vernon (2000) describes as "wellbeing beyond quality of life that revolves around bodies and pleasure" (Vernon, 2000, p. 46).

The research participants identified the following top three fundamental *wellbeing needs* - numbered 1, 2 and 3 below - followed by seven *wellbeing aspirations* (Alzheimer's Society, 2010a, p. ix). In order of priority, they are:

1. Relationships or someone to talk to
2. Environment
3. Physical health
4. Sense of humour
5. Independence
6. Ability to communicate
7. Sense of personal identity
8. Ability or opportunity to engage in activities
9. Ability to practice faith or religion
10. To be free of stigma and discrimination

The first three fundamental wellbeing needs, and the six wellbeing aspirations that follow require little further explanation. Number ten is different; it raises the issue of discrimination and societal attitudes. Not surprisingly, the experience of discrimination was found to be of particular importance to the research participants.

The AS UK research records, the priority concerns in the mind of almost every individual currently living with dementia in the UK is the fundamental right to exercise "self-determination and freedom" of choice as dementia advances and to continue to enjoy, for as long as possible, personal “security and privacy” in all aspects of life (Alzheimer’s Society, 2010a. p. 24).

The taboo nature of dementia diagnosis and the current status of dementia literacy. The problems associated with communicating and delivering awareness of dementia to the community.

Security and privacy are particularly important because the ever-increasing instance of early diagnosis has meant that many individuals become aware all too quickly of the power and “taboo nature” of society’s attitude toward dementia. They realise they are being subjected to discrimination because, unlike cancer, dementia is an “incurable disease” that affects the mind and is all too frequently portrayed in the media as a “personal tragedy”. While some brave individuals and their care partners are vocal in expressing their “desire to be treated fairly”, and lament the “loss of friends” and their “marginalisation” in society, they are few and far between.

The responsibility of the media

The media has a responsibility to be fully aware of the facts surrounding dementia research. It has a duty of care responsibility to avoid superficiality and to take steps to accurately inform the public. On April 20, 2012, the Australian federal government made its announcement on long awaited changes to aged care funding. The announcement, referred to as the Labor Government’s Aged Care Initiative, was in response to the Productivity Commission’s *“Caring for Older Australians’ Report”*.

Although Alzheimer’s Australia has pursued a campaign for some years attempting to educate the public that most individuals who experience memory loss can continue to lead fulfilling lives despite their dementia, almost every journalist and commentator who was interviewed on the morning news shows, before and after the announcement, and even the Initiative wording itself, adopted the biomedical terminology that the late

Professor Tom Kitwood described as representative of an “old culture of care” (Kitwood, 1995 & 1997). Universally, individuals living with dementia were referred to as “suffering from dementia”.

The use of the term “suffering from dementia” is not only ‘political incorrect’, more to the point it is inaccurate and retrogressive. The term hurts the most vulnerable in our community. It stigmatises individuals living with dementia, because it portrays them as little more than poor “hapless victims” only worthy of our pity. It ignores the proven evidence of the value of psychosocial interventions. It also gives the impression that because there is “no cure” for dementia, and because the individual cannot be restored to full health, the pinnacle of the biomedical paradigm, nothing much can be done from the point of diagnosis until death.

Therapeutic nihilism

The message that much can be done, that individuals living with dementia can live a full and fulfilling existence by engagement in a variety of psychosocial interventions, has clearly not reached the media. Perhaps it is not regarded as particularly newsworthy. As a result, journalistic superficiality fuels a particular form of ageism, known as “therapeutic nihilism”, reflecting the “taboo nature” of society’s attitude to memory loss. Malone and Camp (2007, p. 151) believe “the single greatest barrier to the provision of high quality care for persons with dementia is not a lack of resources, but a belief”. And, I would contend, this ‘belief’ has the potential to profoundly influence both societal attitudes and therapeutic outcomes.

Malone and Camp maintain that the general climate is influenced by the media, and by individuals within the aged care system itself, who perpetrate the myth that:

> Because persons have dementia, they are incapable of learning new things, incapable of showing anything but decline, and that the best caregivers can do is be patient and deliver palliative care as the inevitable deterioration of dementia unfolds. This is, in essence, learned helplessness on a system-wide scale. It results, in large part, because of an overemphasis on the deficits associated with dementia (driven by a primary emphasis on diagnosis and treatment of deficits), to the exclusion of acknowledging and utilizing the strengths and abilities still available to persons with dementia (Malone and Camp, 2007, p. 151).

The authors conclude by noting that, “therapeutic nihilism is insidious because it destroys hope and condones acceptance of the status quo”. Such attitudes can foster a climate of perception that dehumanises and even humiliates the marginalised, a group that will soon become an ever-increasing part of Australia’s demographic. Alas, misconceptions of dementia are all too widespread in Australian society.

Dementia literacy

Recently, Low and Anstey (2009) put the concept of dementia to a uniquely Australian “social culture” literacy test. They conducted what they describe as a “the only published community-based study of dementia literacy” designed to identify community knowledge, social beliefs and general awareness of dementia. They found more than 80% of the Australian public think “genetics, old age, brain disease and stroke or mini-stroke contributes to a person getting dementia”; many think other contributing dementia risk factors might include “personal characteristics such as weakness of character (32%) and laziness (22%)”. These misconceptions reveal that dementia is still little understood, explaining somewhat why individuals living with dementia are vulnerable to being stigmatised. Overall, the study found most people (85%), “would not recognize the early symptoms” of dementia and, even though they have a “high rate of recognition” of dementia itself, they are generally "overly optimistic about [the] prognosis". In fact, just over five percent say they expect a "full recovery" from dementia after diagnosis. Not surprisingly, care partners are not as optimistic and tend to think that, "loss of memory is a normal part of ageing". Most care partners would rather not seek an early assessment, because of "the stigma associated with dementia and the belief that little can be done for a person with dementia".

In addition, many Australians from different multicultural backgrounds are reluctant to, and do not, "access support services until they reach the point of crisis" (Ethnic Communities Council of Victoria, 2011 p. 7). Fortunately the Australian health system is unlike that of the United States, where many experience the added fear of losing their health insurance when a positive dementia diagnosis is confirmed.

In terms of promoting quality of life, enabling those living with dementia to remain at home longer, the following evidence and argument from the AS UK report deserves consideration.

In the preface to the 2010 report, Ruth Sutherland, Acting Chief Executive of AS UK, writes that "this piece of work begins to bring together what they [individuals living with dementia] think is important" from across all sections of British society (Alzheimer's Society, 2010 p. vii). Toby Williamson, the report's author, makes some perceptive observations and calls into question the biomedical reliance on proxy interpretations of the dementia experience. Williamson notes that whilst wellbeing and the quality of lived experience are extremely hard to quantify, he believes the description provided by Bowling and Gabriel is helpful. It reads:

> Quality of life is a multidimensional collection of objective and subjective areas of life, the parts of which can affect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experience and the process of ageing (Bowling & Gabriel, 2004, p. 30.

In addition, the report offers recommendations that are pertinent for all nations struggling with the enormity of future dementia care forecasts. Some of the report's points are more salient than others, particularly the basic observation that "the perspective of the person with dementia has for too long been omitted or ignored". Williamson comments (Alzheimer's Society, 2010, p. 46) that health related assessments of the quality of the lived experience are dominated by "disease-oriented measures" that are "not as helpful as once thought". He cites Trigg *et al.* (2007) who write:

> Implicit in the medical model is the notion that there is an optimum level of functioning to which all people should aspire to, whereby those who are impaired or disabled have by definition a poorer quality of life. This leads to the questionable assumption that one cannot achieve positive quality of life in the presence of physical deficits (Trigg *et al.,* 2007, p. 790)

Based on the UK research findings, Williamson is certain "the assumption that dementia inevitably results in poor quality of life from the perspective of the person with dementia is faulty" (Alzheimer's Society, 2010, p. 46).

Williamson then directs us to recent research by Thompson and Kingston (2004), and Ashley and Savitch (2009), and informs us that these authors also maintain that the only individuals who are "expert" in assessing wellbeing and the lived experience in those with dementia are the individuals themselves. It should be understood that until the very recent past there were few appropriate and sensitive wellbeing assessment tools, such as the Talking Mats (pictorial images designed especially for the UK research project) - enabling an individual with all levels of dementia to reliably express an opinion on his or her wellbeing (Murphy, *et al.,* 2010). The failure of the aged care industry to take the time to develop and/or use appropriate tools to obtain an informed response has not only restricted the introduction of psychosocial interventions, it has also limited access by residents living in care to purposeful activities. This failure has limited choice and the capacity for self-determination. It has afforded individuals little opportunity to make decisions about their future. The wellbeing and the quality of the lived experience of those diagnosed early and living in community or in care has therefore rarely been seriously considered.

A person-centred approach to service delivery

One sure way to fully consider and accommodate the wishes of those living with dementia and offer real choice, to enable individuals to remain independent and in their own home, is through the introduction of psychosocial interventions and a person-centred approach to dementia diagnosis, including the formulation of advanced care plans that meet each individual's unique needs. Ian Morton (2000, p. 29) writes that we can trace the initial appearance of person-centred care in the "world of dementia" back to the early 1970s "when Naomi Feil began to insist on the need for empathy and a non-directive approach in her work, developing the origins of what was to become Validation Therapy" (Feil, 1993). He goes on to clarify what he describes as the "intellectual heritage, which has helped to drive the cultural revolution in dementia care that [has] filled the last decade of the 20th century". Morton acknowledges the "richness" in that intellectual heritage that has created a positive brand of person-centred dementia care, and believes its claim on our attention can be found in "the diversity of its origins". He credits and acknowledges many sources, but singles out social psychologists and disability rights campaigners, as well as individuals in the creative therapies and reminiscence movement.

Perhaps the most influential of these individuals was the late Professor Tom Kitwood (1937-1998) who developed the world's first dementia-specific person-centred care model at Braford University in the UK in the 1980s. In his book *Dementia Reconsidered: The Person Comes First* (1997), Kitwood lays out his person-centred approach that has continued to gain currency over the past two decades, but unfortunately is still not widely implemented in Australia. The Kitwood person-centred care model encapsulates the essence of the psychosocial needs of individuals living with dementia and recognizes each person's capacity for enjoyment and selfexpression. By putting the person living with dementia at the centre of the care and decision-making equation, Kitwoodian theory and the person-centred care model, offers an ideal framework to construct culturally appropriate psychosocial interventions for those individuals identified through early diagnosis and others already living with dementia and their care partners.

Conclusion

The nature of AD, the most common form of dementia, is still a mystery and no cure is in sight. The general public's understanding of dementia is superficial and poor media reporting is responsible for much of the confusion and stigma that surrounds memory loss. In the coming decades the baby-boomer generation will ensure that their quest to lead a fulfilling life, after being diagnosed with dementia, will be the catalyst for significant change. The baby-boomers will demand privacy and security and the right to choice and self-determination, when making decisions about their care options. If the development of appropriate psychosocial interventions is not begun now, and if programs and wellbeing options are not in place relatively soon, then the baby-boomer generation's demands will not be met, and quality of care will become a significant human rights issue.

Leading international dementia care specialists recommend that a boost in the development of psychosocial interventions delivered in a person-centred approach is both effective and *the most economical way* to meet the challenges and demands of the future (Bernfeld & Fritsch, 2006).

In the Intergenerational Report 2010, *Australia to 2050: Future challenges* (Commonwealth of Australia, 2010), the Australian Government recognizes the importance of quality of life and individual wellbeing in the sustainability of the Australian nation's future.

It is predicted that dementia is set to become the biggest disability burden in Australia's history by 2016 (Commonwealth of Australia, 2010a;) and, within the next two decades, as many as one in four baby-boomers over eighty-five will probably develop some form of dementia. Half of the baby-boomers, in their ninth and tenth decade of life, will end life living with dementia (Alzheimer's Australia, 2003 & 2005). The cost of maintaining the quality of life and individual wellbeing of this cohort, taking into consideration the cost to care partners as well, will have a dramatic impact on the economy and the sustainability of Australian society (Alzheimer's Australia, 2003). And immigration will play an increasingly important role in the way this demographic conundrum is managed.

The importance of developing dementia-specific stock resources

The authors of the Intergenerational Report 2010 (Commonwealth of Australia, 2010, p. 84) write that, "The wellbeing of a generation is determined by the 'stock' of resources that is inherited from previous generations and the choices that generation makes".

Given the projected future cost of dementia care in Australia, and for the economies of developed nations, it stands to reason that maintaining and continually improving the wellbeing and quality of life opportunities for Australian citizens cannot and should not be easily separated from the development of new and more humane approaches to early diagnosis of dementia and the psychosocial interventions that can enhance wellbeing and dementia-specific service delivery. It has long been recognized that such developments have significant world health implications (Allen-Burge *et al.* 1998). It is also logical to suggest that the creation of a 'stock' of dementia-specific resources is in the long-term interests of Australia and the developed nations. Yet, the paucity of dementia-specific psychosocial interventions, and the research and development of programs that address the wellbeing of those living with dementia, means that there are in reality very few, if any, 'stock' resources that focus on quality of life and community participation to call on. This circumstance presents fundamental challenges that regrettably continue to be largely ignored.

The budget allocation of only $268 million for the early diagnosis of individuals living with dementia over the next five years is evidence of the continued official avoidance of the huge impact of dementia in the near to medium term. It demonstrates that the creation of a worthwhile stock resource of dementia-specific psychosocial interventions, a resource that encompasses all aspects and approaches to the wellbeing and quality of life of those living with dementia, is more critical than ever. When the big surge hits, and the now familiar term ‘tsunami’ has been used in this context, and given that a cure for Alzheimer’s disease and the eighty or more other forms of dementia is most unlikely, we will need all the resources we can muster to face the challenge. Dr Dalia Gottlieb-Tanaka (2004, p. 11), an internationally-recognized dementia expert, believes that “an understanding of the interplay between the cognitive and physical abilities of a person with dementia, and the need for creative expression activities and a therapeutic environment, can make a difference in [wellbeing and] quality of life”.

The Australian government, to its credit, has at least drawn a link between quality of life and wellbeing and economic sustainability by indicating that the development of a ‘stock’ of resources is essential to address the issue of Australia’s future disability burden. In the best interests of all those currently living with dementia (and their care partners), and those likely to be diagnosed in the next few years, these issues must be seriously considered. The gathering of a stock resource of psychosocial interventions, both inclusive and representative of our multicultural diversity, needs to begin immediately.

The Australian Government does not need to reinvent the wheel. We can learn from and follow the lead of governments and healthcare institutions in other developed nations. In particular, the British Government’s *Living well* *with dementia: A National Dementia Strategy* (Department of Health, 2009) and the accompanying *Implementation Plan* (Department of Health, 2009a) has identified and begun to implement seventeen key dementia-specific objectives in National Health facilities across England. The guidelines of leading institutions in Britain, such as The National Institute for Health and Clinical Excellence (2006), recognise the value of the creative expressive arts and other psychosocial interventions in dementia care. Rylatt (2012 pp. 44 & 46) explains that the “arts and creative activities can enable emotional release and provide a means to communicate”, and provide a “range of good to excellent responses” where pleasure and enjoyment are often positive indications of wellbeing in those living with dementia. Another study at the Chelsea and Westminster Hospital, London, between 1999 and 2002, rigorously tested the suitability of the arts in healthcare and clinical settings. In her final report examining the medical literature for the Arts Council of England, Staricoff (2004) cited almost four hundred papers attesting to the value of the use of the creative arts in healthcare. In addition, The UK Department of Health, Arts and Health Working Group were sent “over 1,000 studies which make a powerful case for making investments in art and health” (Department of Health, 2006, p. 12). The studies demonstrate an evidence-based argument for the wider introduction of the creative expressive arts in healthcare and the community. In the United States, the work of the late Dr Gene Cohen (2000, 2000a, 2005, 2006, 2006a) also documents creative aging and the positive impact of the arts on health and wellbeing. The evidence is strong and the need is pressing.

Recommendations

Recommendation One:

The Australian Government should embrace dementia-specific psychosocial interventions and build partnerships to promote the nationwide use of the creative expressive arts across aged care.

Recommendation Two:

A stock resource of psychosocial interventions for those living with dementia and their care partners be developed for immediate and future use.

Recommendation Three:

The principles of the Kitwoodian theory and person-centred care model be the subject of wide dissemination throughout the aged care community, with an emphasis on their adoption across Australian aged care facilities and healthcare.

Recommendation Four:

Dementia be reinstated as a National Health priority.

Recommendation Five:

Individuals living with dementia be fully informed of their care options, and be fully consulted and encouraged to exercise choice and self-determination during the formulation of an advanced care plan.

Recommendation Six:

Culturally appropriate assessment tools be developed to better assess dementia, and the wellbeing and quality of life needs of those newly diagnosed with dementia.

Recommendation Seven:

The Australian Government should adopt elements of the British National Dementia Strategy and its recommendations.

Recommendation Eight:

The Australian Government recommend the adoption of terminology such as “living with dementia” in recognition that those living with dementia can continue to lead fulfilling lives after diagnosis.

Recommendation Nine:

The Australian Government acknowledge the expertise and contribution that dementia-specific healthcare professionals, other than biomedical research scientists (who are already generously acknowledged), make to the quality of life of those living with dementia.

Recommendation Ten:

The appropriate agencies of the Australian Government take cognizance of, and make available, information on outstanding dementia-specific programs in North America, such as *Artists for Alzheimer's* (Zeisel, 2009), *Creative Discovery Corp* (Cohen, 2000), *StoryCorp* (Isey, 2007), *Timeslips* (Basting, 2009), *Opening Minds through Art* (OMA) (Lokon, 2007), *Therapeutic Thematic Arts Programming* (TTAP) (Levine-Madori, 2007), *Memories in the Making* (Kinney and Rentz, 2005, Rentz, 2005) and *The Eden Alternative* (Thomas, 1994 & 1996).

Recommendation Eleven:

A palliative approach to dementia care, one that includes a variety of psychosocial interventions, be implemented at the time of diagnosis.

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