

A race against time: The dementia epidemic

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ABSTRACT

The global prevalence of dementia is expected to double every two decades. Consequently, there is an urgent need for high-quality research to identify effective strategies for providing optimal care to people with dementia and their carers. Currently, research in dementia care is fragmented, which has resulted in a division between the fields of diagnosis and management of dementia including end-of-life care. For example, interventions which have been developed to improve the well-being of the person with dementia and their families focus on discrete elements of the person and their family's experience, such as symptom management, dealing with emotional issues, or planning for the future. A more integrated approach is needed to address gaps in care across the trajectory, while recognizing the multitude impacts on the person affected and their families. This approach will make a meaningful difference to the well-being of people with dementia and their carers, and reduce the burden of the disease on the individual, their family, and society.

Key Words: Burden, carer, dementia, patient-centered

Dementia: A Global Issue of Concern

Driven by the aging population, there has been an explosion in the number of individuals living with dementia worldwide. In 2015, there were an estimated 46.8 million people living with dementia globally.^[1] It is expected that this number will almost double every two decades. Dementia has profound impacts on the individual, their family, and society. People with dementia experience a range of burdens, including impaired functional abilities, increased rates of psychosocial distress, reduced quality of life, changed relationships, and social isolation.^[2] The burden of a dementia diagnosis is also felt by the individual's family, particularly those who take on

the role of an informal carers.^[3] Carers experience high rates of anxiety and depression, poorer physical health, financial pressures, and changes in employment. The global cost of dementia is a staggering \$818 billion, and is expected to rise to \$1 trillion by 2020. The cost of dementia is more than the gross domestic product of some countries at present.^[1] Dealing with the rise of dementia is thought to be a particular challenge in developing countries. In 2015, 58% of those with dementia lived in low-and middle-income countries, with this proportion projected to increase to 68% by 2050.^[1] The high levels of poverty, illiteracy, and reduced availability of resources and care in these countries present significant barriers to meeting the needs of individuals with dementia.

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There is an urgent need to find strategies to meet the needs of people with dementia globally.

What Needs to be Done to Improve the Care and Support Provided to People with Dementia and Their Families?

Improving the quality of care across the dementia care pathway

There are two key limitations of current approaches aimed at improving the quality of care delivered to people with dementia and their carers. First, studies have typically focused on the individual components of care of people with dementia, such as behavior management, dealing with emotional concerns, and planning for the future. This segmented approach does not accurately represent the experience of the person with dementia and their carers. Interventions which focus on only one component of care, such as behavior management, will have limited benefit for the whole person, if other components of care, such as the emotional consequences of the disease, are not addressed at the same time. To achieve a meaningful impact on outcomes, all components of the patient's experience should be addressed simultaneously. Second, research has focused on improving care during one specific phase of the pathway of care for people with dementia, such as at diagnosis or at the end of life. This approach neglects other aspects of the person's experience. For instance, providing an earlier diagnosis may not be beneficial if no effective strategies are in place to support the person with dementia and their carers. Gaps in care across all phases of the pathway should be addressed in tandem. A new coordinated approach to improve the quality of multiple components of care across the trajectory is needed.

Ensuring responsivity to patient preferences

There is a growing recognition that high-quality dementia care is more than just improving outcomes such as earlier diagnosis and managing the symptoms of dementia.^[4] Patient-centered care is the provision of care that is responsive to the needs, values, and preferences of the individual.^[4] Dementia care guidelines incorporate the principles of patient-centered care. For example, the National Institute for Health and Care Excellence guidelines highlight:

1. The human value of people with dementia and their carers;
2. The individual responses of people to their dementia;
3. The importance of the person with dementia's perspective; and
4. The importance of relationships and other interactions to the person with dementia.^[5]

Patient-centered care can improve a range of outcomes, including adherence to treatment regimes, satisfaction with care, and quality of life.^[6,7] Increasing adherence to this model of care, therefore, offers a significant potential to lessen the anticipated burden of dementia worldwide, with benefits for the individual, family, and society. These principles should underpin any attempt to improve the quality of care provided to people with dementia and their carers.

What is the Evidence for the Effectiveness of Strategies to Improve Care across the Dementia Care Pathway?

Improving detection and early diagnosis

Advantages and disadvantages of an earlier diagnosis

Many individuals experience significant delays in receiving the diagnosis of dementia. In Australia, a diagnosis is obtained on an average of 3 years after the symptoms are first noticed, while in the UK, there is a 20-month delay in diagnosis.^[8] In developing countries, the delays may be even lengthier due to reduced access to health-care services.^[9] Current policy in many countries is aimed at increasing the rates of earlier diagnosis of dementia, including the identification of preclinical dementia. Given the lack of a curative treatment for the illness, there is debate as to whether obtaining a diagnosis of dementia or identification of preclinical symptoms as early as possible produces benefits for the individual and their families. On the one hand, an early diagnosis allows individuals and their families more time to plan ahead for changes in function and capacity to ensure that they are equipped with the resources and skills necessary to cope with the journey ahead.^[10,11] Obtaining a diagnosis also allows individuals to plan ahead for their future wishes while they still have the capacity to do so. For example, individuals may appoint an enduring guardian, power of attorney, and complete an advance care directive, which specifies their preferences regarding financial, personal, and health matters.

However, obtaining an earlier diagnosis of dementia can also mean that the individuals diagnosed and their family will experience the adverse emotional impact of a diagnosis for a longer period of time.^[12] Across both developed and developing countries, a diagnosis of dementia is associated with a great deal of stigma.^[13,14] In an Australian study, 60% of the people indicated that they would feel a sense of shame if diagnosed with dementia, while 47% would feel humiliation.^[15] Relationships with friends and family can also change dramatically as a result of the diagnosis. Consequently, it is important to deliver care that is in line with the patient's values and preferences regarding the diagnosis.

Overcoming barriers to the early identification of dementia

Assuming that an earlier diagnosis is preferred, there is a need to find ways of overcoming barriers to delivering an earlier diagnosis. Delays in diagnosis may be attributed to a range of factors. There may be reluctance by the individual and their family to acknowledge symptoms and seek further assessment.^[16] Health-care providers may misinterpret the symptoms of dementia as normal aging.^[17,18] Other barriers identified by health-care providers include lack of training and assessment tools to aid diagnosis, difficulty in disclosing or explaining the diagnosis, and lack of time within consultations for thorough assessment.^[17] System factors, including resource constraints and barriers to accessing specialist assessment services such as memory clinics or neuropsychology services, may also hinder the diagnosis.^[17] Interventions need to be designed to overcome these barriers. Strategies which may be effective in reducing the delay in diagnosis include education to challenge negative views of dementia, training in communicating the diagnosis, and incentives to spend more time on assessment.^[18]

Care and support of people diagnosed with dementia and their families

Once a diagnosis is made, we need to address the full scope of issues experienced by people with dementia and their carers. This includes the symptom, psychological, social, emotional, and financial impacts of the illness.

Dementia symptom management

The behavioral and psychological symptoms of dementia, which include agitation, behavioral disinhibition, aggression, wandering, and psychoses (e.g., delusions and hallucinations), are present for approximately one-third of people with mild dementia and two-thirds of people with severe dementia. These symptoms can be extremely distressing for the individual and their carers. They have been shown to increase the likelihood of psychological distress and depression among carers^[19] and earlier institutionalization of the patients.^[20]

Guidelines for the management of behavioral symptoms of people with dementia recommend that comprehensive assessments are undertaken to establish the antecedents to the behavior; describe the behavior and its consequences, including the frequency, timing, and presentation of behaviors; and identify any social factors, environmental influences, or other physical factors, such as pain, which might trigger these behaviors.^[21] Behavioral and psychological symptoms are potentially modifiable with the use of pharmacological and nonpharmacological approaches. Psychotropic medications are often prescribed for the management of behavioral and psychological symptoms.

However, there are concerns regarding whether these medications are both efficacious and safe.^[22] Behavioral approaches to reducing these symptoms have shown some effectiveness. Systematic reviews have shown that behavioral interventions which involve contingency management (e.g., removing rewards) or behavioral redirection are effective in reducing problem behaviors including wandering, physical and verbal aggression. The interventions which focus on providing education and support to carers to manage these symptoms show mixed effectiveness.^[23] Psychoeducation to change carers' behavior is effective in reducing symptoms if performed in individuals rather than group settings.^[24] Music therapy has also been shown to have some short-term effects, but these were not sustained. However, this evidence is limited by the paucity of high-quality studies found in these reviews. For example, a systematic review by Livingston *et al.*^[24] found only nine studies that met criteria for psychometric rigor. Therefore, further, high-quality evidence is needed in this area to establish the interventions, which may be effective in reducing this symptom burden.

Emotional impact of dementia

People with dementia are particularly vulnerable to emotional concerns, such as depression, anxiety, and distress. Rates of depression vary from 8% to 40%, depending on the population sampled, diagnostic criteria, and method of assessment.^[25] Depression in people with dementia has been associated with early nursing home placement, more hospital admissions, and even increased mortality. Anxiety in people with dementia is receiving increasing attention in the literature, with prevalence rates ranging from 5% to 21% for anxiety disorders and 5% to 71% for anxiety symptoms.^[26] Untreated anxiety has been associated with poorer quality of life, worse physical and neuropsychological functioning, and increased nursing home placement.^[26]

To provide appropriate support for emotional problems, first they must be detected. Clinical practice guidelines highlight the importance of adopting a holistic approach to the assessment of emotional issues, by examining the range of factors that may contribute to these issues, including physical health, medications, interpersonal relationships, and environmental stressors.^[27] It is also recommended that assessments are undertaken at regular intervals using validated instruments. Despite this, 50% of the cases of depression in aged care settings are not picked up and remain untreated.^[28] This is consistent with the findings in primary care. For example, Mitchell *et al.*'s meta-analysis of 41 studies indicated that there was an agreement between general practitioners' (GPs') unassisted diagnoses of depression among primary care patients and diagnoses from structured interviews in only 47% of the cases.^[29]

Health-care providers across care settings report a number of barriers to the detection of emotional concerns, including a lack of knowledge and competencies in recognizing signs and symptoms, conducting assessments, and managing identified concerns.^[30] Education and communication skills training with “booster sessions” can improve knowledge and skills of health-care providers and carers in identifying emotional concerns.^[31] Providing feedback to health-care providers on people’s depression and anxiety scores at the time of consultations (e.g., with GPs) may help improve detection of emotional concerns in clinical practice. Despite the relative simplicity and potential benefits of such an approach, there is a surprising lack of methodologically adequate research in this area.^[32]

Once identified, people with dementia and their carers can play an active role in managing depression and anxiety. Interventions with multiple components, including tailored information and strategies that can support day-to-day tasks, such as taking medications, attending psychological therapy and implementing cognitive and behavioral strategies, as well as peer engagement may be particularly effective.^[33,34] Features of traditional face-to-face education and support programs could be adapted to a more flexible and tailored format for groups that are difficult to reach (e.g., rural populations). For example, online formats might offer a low-cost means of enhancing standard care. Methodologically rigorous research is needed to provide high-level evidence for the potential effectiveness of these interventions.

Social isolation

Social isolation is more prevalent among elderly people (7-24%), compared to the general population.^[35] Fewer studies have focused on social isolation in patients with dementia. A survey of Australians with dementia found that 41% of the people desired more social support and 10% only left the house a few times per month or less.^[36] Perceived barriers to seeking social support include a fear of becoming lost, difficulty in communicating with other people, and a perceived uneasiness of other people with their diagnosis.^[37] Similarly, a 2013 report found that dementia sufferers were at higher risk of social isolation through a loss of social networks and social support; with 70% of people not doing things they used to because of lack of confidence, 68% because they were worried they would get confused, 60% because they were worried about getting lost, and 60% because of loss of mobility.^[38] Other factors that have been linked to social isolation include, poor physical health, mental illness, living alone, geographic location, poor communication, and transport difficulties.^[37] Social isolation often goes unrecognized and unmanaged. This has significant adverse effects for people with dementia

including depression, self-harm or neglect, physical and cognitive disability, and increased mortality.^[35] Feelings of loneliness have also been linked to the development of dementia in older people.^[39] Given the high prevalence and burden associated with social isolation among people with dementia, it is critical that these issues are identified and dealt with.

A review of social interventions in elderly people found that those involving active participation, social activity, and support at a group level were more beneficial, compared with individual level, home-visit, and internet training interventions.^[35] However, these interventions were not specifically tested in people with dementia. Strategies that encourage people with dementia and their carers to interact with others in similar situations (e.g., memory cafes and support groups) can allow participants to share experiences and discuss potential solutions to common issues. For people with younger-onset dementia, work-based interventions which provide safe, supported work outside the home, and include a social dimension may be beneficial.^[40] Further work is needed to examine the potential benefits of social support interventions in dementia populations.

Advance care planning

Any healthy, competent older person can plan for future financial, lifestyle, and medical matters, but it is particularly important for older people with complex health needs as a result of comorbidity, frailty, and disability. Individuals diagnosed with dementia experience gradual loss of cognitive function including worsening of memory, reasoning, and speech, which significantly reduces the capacity for independent living.^[41] This decline in cognitive function impacts on the person’s ability to understand and apply information to make and communicate decisions about their financial, lifestyle, and health matters. People with dementia who have temporary or permanent incapacity are then reliant on their families to make decisions about their lives. When person with dementia’s wishes have not been previously discussed and a trusted person appointed to make decisions on their behalf, this may result in unwanted medical care, conflict between families and/or health-care providers, estate distribution disputes, and financial exploitation. Those called on to make decisions on behalf of the person with dementia may also experience a significant burden as a consequence of their decision-making role.^[42] Therefore, planning for the future is particularly important for individuals diagnosed with dementia.

People who have been diagnosed with dementia and their carers should be encouraged to plan ahead for financial matters by making a will and/or appointing an enduring

financial power of attorney. They should be also encouraged to plan ahead for lifestyle (e.g., future living arrangements) and future medical care. Advance care planning (ACP) is a process, “whereby an individual, in consultation with family members, health-care professionals, and/or significant others, is able to discuss and document decisions about his or her future medical care, in case he or she later experiences periodic, temporary, or permanent loss of capacity.”^[43] ACP may take the form of a written instruction describing the care a person would want or does not want and the values that guide the person’s decisions (i.e., advance directives or living wills). People may also choose to appoint someone to make medical decisions for them should they lose capacity (i.e., substitute decision maker). For maximum benefit, it is recommended that these discussions occur as soon as possible after a diagnosis of dementia to ensure meaningful participation of the person diagnosed.^[44]

Despite the potential benefits, the rate of uptake of planning ahead is low among individuals with dementia. A recent Australian survey found that 50% of the carers reported that the person with dementia did not have an advance directive in place, while a further 10% were unsure.^[45] Many older adults are unaware or have a poor understanding of their legal rights.^[46] Providers may be reluctant to deliver advance care recommendations due to the specialist knowledge required, low confidence in their ability to provide this advice, lack of time available, and an unwillingness to raise the issue of death soon after a diagnosis.^[47,48] Family carers may also be reluctant to discuss ACP with their loved one.^[49] Health professionals report critical knowledge gaps about relevant law, such as the rules that apply when a person loses capacity and the role of substitute decision makers.^[50,51] Strategies that improve community awareness about the availability of financial, lifestyle, and medical planning, as well as their rights and responsibilities associated with these matters are needed. For health and legal professionals, strategies that incorporate reminders, audit and feedback, and education and training may increase the rate at which the preferences of people with dementia are discussed and documented in health and legal settings.

Providing care to carers

With the trend for reduced access to hospital and respite care and longer waiting times for long-term residential care, it is expected that the burden of supporting people living with dementia will be placed increasingly on informal carers. Carers perform a multitude of roles, including managing symptoms, assisting with activities of daily living, navigating a complex, and often confusing health-care system to ensure that the person is receiving the care he/she needs, providing emotional support, and encouragement

to maintain functional independence.^[52] The burden on carers of people with dementia is among the highest of all carer groups.^[53] A high proportion of carers report at least one adverse physical or emotional concern. Depression is considerable, with prevalence rates ranging from 15% to 32%.^[54]

Many carers feel unprepared for their role, and consequently, often report feelings of inadequacy and low self-efficacy.^[55,56] Appropriate support should be provided to carers to develop the skills required to take on this demanding role. Without adequate support, the demands of caregiving may become overwhelming, leading to an increased likelihood of carer burnout and the decision to place the person in institutional care.^[57] Supporting carers involves not only assisting them to manage the needs of the person with dementia, but also their own needs which may be severely impacted by the demands of caregiving. Consequently, carers should be provided with coping strategies to ensure that their own well-being is maintained. Interventions tested thus far have failed to capture the range of the roles that carers perform. A recent systematic review of carer interventions found that the scope of training provided as part of these interventions was limited to only some domains, such as direct care and symptom management.^[58] Intervention strategies which recognize the full scope of the caregiving experience, including a recognition of the impact of the role on the carer’s well-being, are more likely to lead to improved outcomes for both the carer and person with dementia.

The mode of delivery of interventions to carers is important. Traditional face-to-face carer education and support programs can be logistically difficult to deliver. The time-limited nature of these programs may also present difficulties with providing carers with adequate and ongoing support in the areas in which they need it most. To maximize the reach of these interventions, it is timely to examine how features of traditional programs can be adapted to a more flexible and tailored online format. Web-based programs may assist in overcoming some of these challenges.^[59] Internet interventions offer a low-cost means of enhancing standard care by delivering targeted education and support to carers. This delivery mode has several advantages, including:

1. Multiple modes of information delivery including videos, diagrams, and written material;
2. Features that overcome poor health literacy;
3. Ability to tailor information according to circumstances and preferences of the user;
4. Ability to be centrally updated as new evidence becomes available; and
5. The opportunity to link carers through online forums.

Systematic reviews of web-based interventions for carers of people with dementia indicate that interventions which include multiple components, tailored information, and strategies for peer engagement are particularly effective for this population.^[33,34] However, the poor methodological quality of previous studies in this area limits interpretation of findings. Therefore, there is an urgent need to conduct methodologically rigorous research to provide high-level evidence for the potential effectiveness of e-health interventions for carers of people with dementia.

Future Directions

The findings of this review highlight a paucity of evidence, and in particular high quality evidence, to guide the future development of policy and practice in the area of dementia care. Methodologically rigorous research utilizing randomized controlled trials are urgently needed to inform future policy and practice in dementia care. Where randomized controlled trials are not feasible for practical or ethical reasons (e.g., where the control group should not be denied access to enhanced care), alternative research designs such as multiple baseline or stepped wedge should be considered. The scarcity of rigorously conducted trials is likely due to the time, expense, and expertise it takes to conduct such studies. Intervention trials can take a great deal of time to develop and implement and result in slower publication outputs than descriptive studies. Improving education and training in the use of rigorous research design and methodology to researchers and clinicians engaged in research in this area may go some way in improving the quality of evidence.

While the data reviewed in this article suggest there may be some effective intervention strategies for improving the care provided to people with dementia and their carers, a more holistic approach is required which simultaneously addresses all aspects of these individuals' experience. Such an intervention might comprise a "package" of strategies aimed at people with dementia and their families which integrates together the effective strategies described in this article. Individuals could access components of the package according to their needs. For example, behavioral symptoms may not be an issue for a particular individual, but they may be interested in knowing more about ACP. This patient-centered, holistic approach has potential to greatly increase the impact of the intervention in improving the well-being of people with dementia and their carers.

Although beyond the scope of this article, the recognition of emerging areas of research in the field of dementia care which may reduce the impact and burden of the disease is worthy of further attention. One emerging area is the

prevention of dementia by identifying potentially modifiable risk factors. Although the evidence for the factors which may influence the risk is unclear, there is some preliminary suggestion that health behaviors such as physical activity, smoking, mid-life obesity, and mental engagement may influence one's risk of developing dementia. Given the potentially significant impact of reducing incidence and prevalence of dementia through reduction of these risk factors, further high-quality research is warranted.

Conclusion

While dementia is a growing area of research, we need to ensure that this research is conducted in a way to derive the maximum benefits for individuals with dementia, their carers, and the society. Developing approaches to care which address the needs of the person as a whole and are tailored to their preferences, and testing these approaches using rigorous experimental methodology will advance our understanding of dementia. This is urgently needed to reduce the global impact of this important health-care issue.

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Conflicts of interest

There are no conflicts of interest.

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