



The Underserving Sick: Preparing for the Next Wave of Challenges in the Care of Older Adults with Dementia after COVID-19 Pandemic in Thailand

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Received: 14 March 2022; Revised: 1 August 2022; Accepted: 8 August 2022

Abstract

COVID-19 pandemic has been a profound shock to the widespread global healthcare system and social support services, Thailand included, raising a serious health challenge and concern to older adults with dementia. To date, there is a dearth of specific and tailored guidance or public messaging on supporting people living with dementia and families in the face of COVID-19 outbreak, particularly in the context of Thailand. As the country is aging rapidly along with the rising number of people with dementia, this paper brings to the forefront the impacts of COVID-19 and its measures on older adults with dementia amid the COVID-19 pandemic, and the approaches taken to overcome the challenges, offering a critical perspective and insights into recommendations for the next wave of COVID-19 or the next pandemic. Proactive solutions for ensuring safety, improving the quality of dementia care while maintaining social interaction in an unprecedented situation are discussed, including through the use of innovative technologies, supporting intergenerational connections, improving navigation of community supports and the healthcare system, and promoting continued education for healthcare providers.

Keywords: COVID-19 Pandemic in Thailand, Dementia, Healthcare Systems, Older People with Dementia in Thailand, Underserving

Introduction

The arrival of the coronavirus disease 2019 (COVID-19) has raised an unprecedented, serious health concerns to older adults with dementia (Denning & Lloyd-Williams, 2020; Wang et al., 2020). Evidence has shown that older people living with dementia are among those hardest hits not just by the COVID-19 pandemic, but also by the negative impacts of the mitigation measures taken worldwide to curb the spread of the virus (Numbers & Brodaty, 2021). For example, older people with dementia are particularly susceptible to contract COVID-19 given the deterioration in cognitive functions, limiting their ability to understand and comply with the recommended infection control measures (Mok et al., 2020; Numbers & Brodaty, 2021; Wang et al., 2020). Recent studies found that older adults with dementia are at greater risk of worsening memory, behavioral, and psychological symptoms, resulting from the social distancing and lockdown measures (D'Cruz & Banerjee, 2020; Denning & Lloyd-Williams, 2020; Numbers & Brodaty, 2021). In addition, older people with dementia have a relatively higher risk of experiencing serious complications and death compared with those without dementia (Atkins et al., 2020; Numbers & Brodaty, 2021; Livingston et al., 2020; Wang et al., 2020).

Dementia is a syndrome resulting from a variety of diseases and injuries mainly Alzheimer and stroke, affecting memory, other cognitive abilities, and behavior (World Health Organization, 2021). Across the globe, there are approximately 50 million people living with dementia and this number is predicted to reach 82 million in 2030 and triple in 2050 (World Health Organization, 2021). Of these statistics, nearly 60% of people suffering from dementia reside in low- and middle-income countries (World Health Organization, 2021). The dementia incidence increases exponentially with advancing age, from 65 to 90 years (Prince et al., 2015). In Thailand, there is a limited data available on the consensus of people living with dementia, both the prevalence and diagnosis



rates. However, based on the 2014 population data, it is estimated that the prevalence of dementia among older people in Thailand was 8.1% (Aekplakorn et al., 2016). At this estimated rate of prevalence, it is forecast that the number of older people with dementia in Thailand will reach to over 1.4 million by 2035 given a rapid increase in the proportion of older population (Institute for Population and Social Research, Mahidol University & Foundation of Thai Gerontology Research and Development Institute, 2016).

Dementia represents substantial impacts not only on human costs to individuals, families, and societies at large, but also on the worldwide economy with the estimated costs of US\$1 trillion annually (Patterson, 2018). In Thailand, the costs associated with dementia in 2015 was estimated at around US\$2 billion (Alzheimer's Disease International, & Alzheimer's Australia, 2014). While the number of older persons with dementia is increasing, concerns about the lack of awareness and understanding of dementia remain a challenge, contributing to fears, stigmatization, and the delay in diagnosis and treatment (World Health Organization, 2021). Starting in May 2017, WHO has recognized dementia as a public health priority, endorsing the global action plan on dementia and urging countries to develop a national policy on dementia by 2025 (World Health Organization, 2017). Yet, dementia is still not a national priority in most countries (Adulyanukosol, 2019; Lhimsoonthon et al., 2019; Sun et al., 2020). To date, there are only 6 member states in the Asian continent having national dementia plans in place, including Macau SAR, Indonesia, Japan, Republic of Korea, Chinese Taipei, and Singapore (Barbarino et al., 2020). In Thailand, efforts have been made to develop the practice guidelines and model of dementia care across all care settings. However, studies about the model of care and effectiveness of program for older people with dementia in Thailand are scarce (Lertkratoke et al., 2021).

As Wang et al. (2020) mentioned, dementia is a pandemic in an aging society, posing a significant challenge for people living with dementia and their families when another pandemic hits—COVID-19. While the COVID-19 crisis has posed a great threat to all humankind, the double hit of dementia and COVID-19 pandemics place a heavy burden on older people with dementia and their families, marking the worrying inadequacy of the national policy responses to the challenges particularly in Thailand. The current health and social service provisions are not well equipped to effectively manage older adults with the new, yet growing complex care needs.

There appears to be little information and knowledge on dementia in the time of COVID-19 pandemic, particularly in the context of Thailand. This paper aims to critically analyze and examine the impacts of COVID-19 and its measures on older adults with dementia amid and after the COVID-19 pandemic, and the approaches taken to overcome the challenges. A desk review of the available articles, books, government reports and census, policy documents, clinical guidelines, health reports, and other relevant documentation on older people with dementia in the time of COVID-19 specific to the Thai context was adopted. All peer-reviewed articles and grey literature that pertained to older people and informal caregivers, dementia, healthcare professionals involved in dementia care, and the COVID-19 pandemic were consulted. Based on the literature analysis and our understanding of a double pandemic, we offer a critical perspective, insights and recommendations for the next wave of COVID-19 or the next pandemic.

The Effects of COVID-19 on Older Adults with Dementia, Families, and Healthcare Professionals

Older Adults with Dementia

Older adults are among those most affected by emergency situations and crises, and this has been especially true in the time of COVID-19 pandemic (United Nations, 2020a). The COVID-19 pandemic has placed a



spotlight on the weakness of healthcare system and highlighted the vulnerability of older persons carrying the disproportionate burden of severe COVID-19 associated illness and death (Tousi, 2020; Bianchetti et al., 2020; United Nations, 2020b). While the crisis has become a challenge for older people, it is burdensome particularly for vulnerable population living with dementia (Tousi, 2020; Dening & Lloyd-Williams, 2020; Manca et al., 2020; Wang et al., 2020). Recent studies found that older adults with dementia are particularly vulnerable to the pandemic and its negative consequences, due to a variety of reasons such as impaired cognitive functions, neuropsychiatric symptoms, and limited access to healthcare and resources. For example, Numbers & Brodaty (2021) indicated that older people with dementia face unique challenges during the COVID-19 pandemic and are at increased risk of contracting COVID-19 infection and developing severe illness, given the cognitive deficits this vulnerable group bears. A study by Docherty et al. (2020) found that dementia is a common comorbidity in older adults with COVID-19 infection and is a predictor for mortality outcome. Due to the shortage of ventilators, older people with advanced dementia are unlikely candidates for ventilator support in the time of crisis (Tousi, 2020). The increased morbidity and mortality associated with COVID-19 of long-term care residents, where the dementia prevalence is disproportionately high, have been reported in the United States (Soucheray, 2020), United Kingdom (Holt & Butcher, 2020), Canada (Hsu et al., 2020), China (Verity et al., 2020), and South Korea (Kim, 2020).

The COVID-19 pandemic alongside the infection control measures have caused disruptions to the routine and lifestyle, creating the detrimental effects on the cognitive abilities, behavioral, and psychological symptoms of older adults with dementia (Barguilla et al., 2020; Boutoleau-Bretonnière et al., 2020; Manini et al., 2021; Manca et al., 2020; Porcari et al., 2020). A recent study conducted in France, for instance, found that the COVID-19 confinement contributes to the increased social isolation and loneliness, deteriorating cognitive function and worsening neuropsychiatric symptoms (i.e., depression, anxiety, apathy, agitation, and hallucinations) of older adults living with neurocognitive disorders (Boutoleau-Bretonnière et al., 2020). Similar findings have been reported in the US (Ward et al., 2020), Italy (Manini et al., 2021), and Spain (Barguilla et al., 2020). A concern unique to older people with dementia during the enforced restrictive limitations and lockdown in terms of: having higher risks of violence, abuse, and neglect; experiencing fear and distress; and delaying in treatment and care that exacerbate disease progression has also been raised (Tousi, 2020; Hsu et al., 2020; Numbers & Brodaty, 2021). In Thailand, early in the pandemic, the government embarked a number of robust measures, including serious restrictions on freedom of movement based on age and limitations of outpatient visits for non-urgent cases. Though Thailand has successfully gone through the first wave of the pandemic, older people and those with dementia have often been overlooked, bearing the brunt of the COVID-19 impacts (Lloyd-Sherlock et al., 2020).

Families and Caregivers

Worldwide, the informal caregivers (i.e., family members and friends) are the cornerstone of care for older people living with dementia (Prince et al., 2015). Most significantly, the demand of care and support provided by the unpaid caregivers is rising rapidly in low- and middle-income countries including Thailand, given the limited supply of services and resources (Prince et al., 2015). Compared with the care provided by caregivers of people with other chronic conditions, caring for older people with dementia requires more hours of care and extensive assistance (Alzheimer's Association, 2020a). While dementia hardens and shortens the lives of those



affected, it has the greatest impact on the quality of life, both of the older individuals living with the disease and their family (Prince et al., 2015; Alzheimer's Association, 2020a).

The COVID-19 safety measures (e.g., suspension of outpatient services and day-to-day activities, visitation restrictions, and confinement) have particularly highlighted increased vulnerabilities not only to older people living with dementia, but also to the informal caregivers who are largely forgotten during the pandemic (Chan et al., 2020; Mok et al., 2020; Numbers & Brodaty, 2021). A limited but available study on the experiences and needs of dementia caregivers during the pandemic reported that caregivers of people with dementia face multifaceted challenges such as dealing with the changes in the daily routines/activities, managing an emergence or worsening of behavioral and psychological symptoms, experiencing higher levels of emotional distress and physical difficulties, and handling disruption in working practices and financial constraints (Vaitheswaran et al., 2020). With increasing demand of care, during and after the pandemic, this highlights the need for caregiver support to help these underserved populations coping with stress and anxiety while maintaining the family caregiver role (Hado & Feinberg, 2020). In the absence of national data and government guidelines directed specifically towards people with dementia and unpaid caregivers during the pandemic in Thailand, findings about the impact of the COVID-19 pandemic on both those living with the disease and their families remains a challenge.

Healthcare Professionals

The COVID-19 pandemic poses multiple challenges for healthcare professionals involved in the care older persons living with dementia (D'Cruz & Banerjee, 2020). In addition to the challenges in terms of: the availability of guidance; access to personal protection equipment; testing capacity; visiting policies; and financial implications, healthcare professionals including nurses are struggling to provide appropriate dementia care while adhering to the infection prevention protocols and maintaining patient safety (D'Cruz & Banerjee, 2020). The delivery of dementia care in the time of the pandemic is often undertaken in stressful and resource poor settings, with inadequate structural provisions, infection control training, and safety equipment (Alzheimer's Association, 2020b; D'Cruz & Banerjee, 2020). More specifically, Long-Term Care (LTC) settings, including nursing homes have been last in line for the protective equipment and testing (Banerjee & Estabrooks, 2021). This has the potential to contribute to greater risks of mental health problems, the fear of becoming infected and infecting the underserving ill, and physical exhaustion due to staffing shortage and protective gears (Liu et al., 2020; Mok et al., 2020).

In Thailand, recognizing the growing needs of LTC, the government has taken several steps towards developing the LTC system. However, the current LTC system in Thailand has no government body responsible for the overall development and management, particularly in an unprecedented time (Asian Development Bank, 2020). This makes it difficult to determine the effect of the pandemic on healthcare professionals and to maintain operations with limited government guidance and resources regardless of the healthcare settings.

Approaches Taken to Overcome Challenges in the Time of Crisis

A national response and government plans for addressing the growing challenges of a double pandemic (dementia and COVID-19) are imperative to protect the public, including people living with dementia and their families. Although the scale and impact of COVID-19 varies from country to country, success in reducing the number of COVID-19 cases, deaths, and long-term sequelae require special consideration in combination with a well-organized and resilient healthcare and social protection systems (Alzheimer's Association, 2020c; Fisher



et al., 2020). Addressing the vulnerabilities and challenges facing people living with dementia and caregivers during the pandemic not only save lives of those affected, but also protects the society at large, reducing the strain on healthcare systems and subsequently healthcare costs (Alzheimer's Association, 2020c). National dementia guidelines and practices in the time of pandemic for older people with dementia, informal caregivers, and/or healthcare professionals at different care settings (e.g., home, community, hospital, and LTC) have been made publicly available in countries such as the US (Alzheimer's Association, 2020b; Centers for Disease Control and Prevention, 2020), the UK (National Health Service, 2021), Australia (Australian Government, Department of Health, 2020), Ireland (The Alzheimer Society of Ireland, 2020), Scotland (The Scottish Government, 2020), Korea (Kim, 2020), and China (Chinese Society of Geriatric Psychiatry et al., 2020).

Given the unique challenges facing people living with dementia and families, several steps have been taken to lessen the impacts of COVID-19, both in the community and long-term care settings. In England, a variety of approaches have been implemented amid crisis, particularly for those living in their homes, ranging from maintaining physical and mental wellbeing, prescribing social connection, utilizing innovative techniques for remote assessment and virtual diagnosis, to ensuring competency in palliative and end-of-life care (National Health Service, 2021). In Scotland, the government has expanded the national action plans to include the protection and support for people with dementia and their informal caregivers, taking the human rights and equalities into consideration. For example, in response to COVID-19, the Scottish government has worked in partnerships with Alzheimer Scotland, local health and social care sectors to improve the provision of dementia care and the design of post-diagnostic services, including ensuring access to the required services and maximizing the impact of telecare (The Scottish Government, 2020). Funding has been allocated to support dementia services and research through service innovation, prioritizing training support for those involved in dementia care to enhance service quality and consistency (The Scottish Government, 2020).

As the country first affected by the COVID-19, the Chinese Society of Geriatric Psychiatry and Alzheimer's Disease Chinese have released an interdisciplinary solution, providing expert consensus on mental health and psychosocial support to guide the continuous dementia care in China (Chinese Society of Geriatric Psychiatry et al., 2020). This includes online psychological counseling services offered for older individuals living with dementia and their families at no cost, minimizing the compound effects of the COVID-19 and dementia (Wang et al., 2020).

In Australia, long-term care facilities, where the number of people with dementia is disproportionately high, have been trailing a range of methods to help combat social isolation among residents during the COVID-19 through the video chat with families, handwritten letters, and window visits (Australian Government, Department of Health, 2020). A number of services have been offered to address the vulnerabilities facing people living with dementia and families in Ireland, including Dementia Advisers, National Helpline, Online Family Carer Training, and Alternative Activity Therapy (The Alzheimer Society of Ireland, 2020). In Thailand, the Department of Older Persons, Ministry of Social Development and Human Security (2020) has developed the prevention and control of COVID-19 in nursing homes and long-term care facilities, such as the use of only one entrance-exit door, restrictions of outsiders, referral of a high-risk older resident to the hospitals and disinfection of high-touch surfaces and shared equipment.



Recommendations for the Next Wave of Challenges

In Thailand, despite an alarming rise in the number of older people with comorbidities, including dementia, data on both the incidence and prevalence of people living with dementia is scarce. The COVID-19 is not only disrupting routine operations but also exacerbating data inequalities, shedding lights on the importance of timely and disaggregated data. Such data are critical in understanding, managing and mitigating the health, social and economic consequences of the COVID-19 pandemic (United Nations, 2020b). To date, efforts have been made to develop the guidelines and actions directed specifically towards people impacted by dementia. However, the specific and tailored knowledge and information on dementia care during the pandemic in Thailand remains a challenge. The data on the prevalence of COVID-19 related illness and death among people with dementia is also severely limited. This lack of data limits the ability of the government and stakeholders to design short-term responses and accelerated efforts, as well as to monitor progress and identify gaps in the fight against COVID-19, particularly in relation to dementia (Barbarino et al., 2020). This highlights a critical need for investments in the data and statistics to inform policy responses, maintaining adequate coverage and protection of a ‘doubly vulnerable’ population.

In view of the widespread global staff and medical shortages, it is imperative that healthcare providers, from physicians and nurses to both formal and informal caregivers, have dementia-specific and tailored guidelines to inform care and facilitate difficult decision making, as well as an appropriate dementia training to maintain social interaction and provide extra support to older people with dementia in the time of social distancing (Barbarino et al., 2020). The existing under-resourcing of health and social care systems, exacerbated by the crisis, will not be enough to adequately support the increased vulnerabilities of older people with dementia and achieve the Sustainable Development Goals (SDGs), aiming to ‘leave no one behind’ and put the vulnerable groups at the top of the 2030 Agenda (United Nations, 2020a). In fact, the Barbarino et al. (2020) calls on all governments to include dementia in the national and health agendas, integrating humanitarian response plans that consider multilayered supports for people living with dementia in an unprecedented time.

The COVID-19 has highlighted a need for innovations and adaptations in the provision of dementia care at all levels to facilitate high-quality patient care that meets the needs of families and patients while supporting adherence to social isolation and quarantine (Barbarino et al., 2020; D’Cruz & Banerjee, 2020; Mok et al., 2020; Roach et al., 2021; Wang et al., 2020). The transformative and innovative approaches to dementia care such as telemedicine (i.e., remote cognitive testing), virtual dementia cafes (Hung & Mann, 2020), tablet-based interventions and social robots (Hung & Mann, 2020) are particularly useful in planning for the next wave of COVID-19 or the next communicable diseases. Given the emerging, yet growing complex needs for LTC of the older population, it is vital that the government recognizes the need to improve coordination with the healthcare system and invest more in healthcare workforce (e.g., wages, training, opportunities for career progression), prioritizing care quality and safety of the underserving ill (Asian Development Bank, 2020). In Thailand, policy measures and efforts to ensure adequate staffing, limitation of staff movement between multiple care settings, access to and proper use of personal protective equipment, appropriate healthcare training to implement infection control protocols, and periodic surveillance testing are critical for protecting safety and welfare of both healthcare personnel and residents (Barbarino et al., 2020).

Evidence suggests that Thai people with dementia often do not undergo evaluation at the onset of dementia, with 72% of those affected by the disease not receiving the treatment, leading to increase personal, social, and



financial burdens (Lhimsoonthon et al., 2019). The missed and delayed dementia diagnosis is largely due to the lack of dementia knowledge and awareness particularly among primary healthcare providers including nurses and informal caregivers, and the prejudices faced by those who have the disease (Lhimsoonthon et al., 2019). As nurses and other health workforce are well positioned to support in the provision of dementia care, including screening and referral services, there is a pressing need for additional competencies to cope with the challenges. This may include incorporating dementia-related content and training into academic programs, strengthening healthcare professional's ability to support early diagnoses and provide effective care planning at all stages of dementia. The incorporation may be through continuing education and interprofessional training, and preparing healthcare professionals involved in the dementia care for crises or emergency situations (Alzheimer's Association, 2020a).

The majority of older adults with dementia live in their own homes, cared for by informal caregivers, usually unpaid (Jackson et al., 2019). The COVID-19 pandemic is exacerbating the demand of care in the face of quarantine rules and other preventive measures, highlighted the need for caregiver support (Altieri & Santangelo, 2021; Canevelli et al., 2020; Mazzi et al., 2020; Cohen et al., 2020). A recent study by Masterson-Algar et al. (2022) reveals that COVID-19 has led to a reduction in support offered by health and social services and a move towards remote service delivery for older people living with dementia and their caregivers. Nonetheless, there is a clear evidence gap on how remote support and digital technologies (e.g., video conferencing, telehealth) were adapted during the pandemic to meet the needs of older people with dementia and their carers (Masterson-Algar et al., 2022). Future research should explore experiences of older people with dementia and their family carers with technology use, as well as the barriers to access remote services.

A more concerted research effort to promote and inform consideration of dementia in national education and health policies is also critical. This knowledge can serve as a guideline for policymakers, healthcare professionals, and academics in their fight to protect older people's rights. As Thailand emerges from the COVID-19 pandemic, the lessons learned offer policymakers and stakeholders an opportunity to address the deep-rooted weakness and systemic issues particularly when it comes to dementia in order to better prepare to meet the surging challenge ahead.

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