*Background paper*

**Enhancing the well-being of older adults and their families affected by dementia**

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**Population ageing and the growing number of older adults with dementia**

Population ageing is one of the most prominent demographic changes we are experiencing now. According to UN DESA, in 2022, 771 million people were aged 65 and over globally. By 2050, this number is projected to increase to 1.6 billion. The number of people aged over 80 is growing even faster and will triple between 2020 and 2050 (UN DESA, 2022).

With the ageing of the population, the number of people with dementia is also rising. Currently, more than 55 million people live with dementia worldwide, and nearly 10 million people are newly diagnosed every year (WHO, n.d.). By 2050, the global number of people with dementia is projected to increase to 139 million. The number of people with dementia in the Asia Pacific region alone is estimated to reach 71 million by 2050 (ADI, 2014).

The increase in the number of dementia cases means that more families will have to bear the economic, physical, and emotional burden of caring for their loved ones with dementia. Hence, developing effective prevention and support systems for people with dementia and their caregivers is imperative in order to ensure the well-being of older adults and their families.

In preparation for the 30th Anniversary of the International Year of the Family 2024, I aim to address three key questions related to dementia's impact on older adults and their families in Asia: 1) How does dementia impact older adults and their families in Asia? 2) What’s being done to support them? 3) Given demographic changes, how can we enhance the well-being of older adults and their families affected by dementia? In examining current policies and measures, I focus on the case of South Korea, one of the most rapidly ageing countries in Asia.

**Impact of dementia on the well-being of older adults and their families**

*Caregiving burden*

Dementia is a relentless disease without a cure, lasting for 4 to 20 years. According to a 2015 report by Alzheimer’s Disease International, the cost associated with dementia in the Asia Pacific region is estimated to be around US$185 billion (ADI, 2015). This estimate encompasses costs related to 'informal care (such as unpaid family carers), social care (community and residential care), and medical care (treatments in primary and secondary care)' (ADI, 2015, p.10). In Korea, caring for a dementia patient is estimated to cost around US$16,138.65 per year (National Institute of Dementia, 2022). Given that the average annual income of Korean families is around US$42562, the cost of caring for a person with dementia creates a significant financial burden.

The cost of dementia extends beyond monetary expenses. As dementia progresses, individuals lose the ability to perform daily activities and become increasingly dependent on others for care. According to a WHO report, 'needs for care tend to escalate over time, from increased support for household, financial, and social activities, to personal care, and for some, almost constant supervision and surveillance' (WHO, 2012). Additionally, some people with dementia exhibit behavioral or psychiatric symptoms, presenting further challenges for their families and caregivers.

As caregivers' involvement in care increases, they experience secondary stress. In addition to their role as caregivers, they have to manage competing demands and roles, such as child care and work. These conflicting roles can lead to greater strain, fatigue, and health problems (Vitaliano, Zhang, & Scanlan, 2003). One study in Korea reports that family caregivers who had a job had to reduce their work hours by 14 hours per week and 27% of them quit their job to care for a family member with dementia. On average, family members spend 6-9 hours daily for caregiving and many caregivers have to compromise their other roles because of their caregiving role (Ministry of Health and Welfare, 2011). As such, dementia not only affects the well-being of the patients themselves, but also casts long-lasting impact on the well-being of their family caregivers.

*Mental and physical health consequences of caring for people with dementia*

Due to the reasons mentioned above, family caregivers are vulnerable to mental and physical health problems. On average, caregivers, especially primary caregivers, of people with dementia show elevated levels of depressive symptoms and anxiety and lower levels of well-being than non-caregivers (Akkerman & Ostwald, 2004; Cuijpers, 2005). Dementia caregivers also show poorer self-rated health and greater physical health problems than non-caregivers (Schulz & Martire, 2004). Because dementia often progresses over an extended period of time, family members often experience anticipatory grief, which can aggravate their caregiving burden (Holley & Mast, 2009).

*Social isolation of families affected by dementia*

Finally, dementia has social consequences for both people with dementia and their families. Studies indicate that lower MMSE scores are associated with a loss of friends and neighbors (Aartsen et al., 2004), and subjective memory problems are linked to reduced perceived support from friends among older adults (Ha & Pai, 2018). Caregivers are also at a greater risk of social isolation due to a lack of opportunities and time to interact with others (Hajek, Kretzler, & König, 2021). In a qualitative interview conducted in Korea, families of older adults with dementia shared experiences of social stigma attached to being dementia patients and expressed the need for more social contact and engagement to maintain cognitive functioning (Park et al., 2022).

**Current practice and policies in Korea to support families affected by dementia**

Research has shown that community support and public health efforts can not only reduce the financial and physical burden on family caregivers but also help them maintain their crucial role as primary caregivers. Supporting the families through various interventions can also delay nursing home admission (WHO, 2012). Interventions are most helpful when they are structured, intensive, multicomponent, and started earlier in the disease course (Brodaty & Luscombe, 1998; Pinquart & Sörensen, 2004; WHO, 2012).

South Korean government has taken several policy measures to support the people with dementia and their family caregivers. It has established and implemented the Dementia Management Comprehensive Plan since 2008 and updated the Plan every four years (2008, 2012, 2016, 2020). These national strategies include blueprints for managing dementia through prevention, early detection, treatment, and care. They emphasize early intervention for people with dementia and their family caregivers to reduce the social and economic cost of dementia and to improve the quality of life for individuals with dementia. Additionally, in 2017, the government announced the ‘National Responsibility Policy for Dementia Care,’ indicating that the state has the primary responsibility for caring for people with dementia. With this policy, 256 Dementia Centers have been established across the nation to support dementia patients and their caregivers in community settings (Ministry of Health and Welfare, 2021).

There are several measures specifically designed to reduce families’ burden of caring for people with dementia. First is the National Long-term Care Insurance. While this program was initially developed to support individuals with restricted functional abilities, special considerations have been made for individuals with dementia. Since 2014, people with mild dementia who can perform daily tasks are eligible for up to 2 hours of support at home per day or can use day care centers up to 3 times (8~12 hours/day) per week. When the patients’ health conditions deteriorate and can no longer perform daily activities, they can apply for reevaluation and, if eligible, can get full-time care at publicly funded nursing homes or at home.

Second, Dementia Centers provide several services and programs for community residents such as early dementia case detection program, cognitive exercise classes, prevention classes, dementia education, family support groups and self-help groups, and case management. It offers free dementia screening and those who are suspected to have dementia are given a more detailed examination or referred to a clinic for a follow-up.

Third, several programs at the community level provide respite care for family members. The 'Vacation for Families' program allows dementia patients receiving home-based care to stay at a nursing facility for up to 6 days per year while their family members take a break. For those with late-stage dementia, families can choose to receive 6 days of 24-hour care at home.

Fourth, efforts are being made to reduce social stigma around dementia, educate the general public about the disease, and create communities that are safe for people with dementia to live in. Dementia friendly community programs are developed across the nation and both people with and without dementia and residents of diverse age groups are invited to participate in these programs. To help families find the lost person with dementia, arrangements are made with the police and emergency response systems to detect and recognize dementia patients who are lost.

Finally, public guardians are available to help people with dementia who do not have family members to take care of legal or financial matters and yet cannot afford to hire a professional or an attorney (there are income criteria for this service). These guardians assist dementia patients when they need someone to sign legal documents, enter into a contract for social welfare services or with facilities, or manage their bank accounts

**Future Directions**

While many policy efforts are being made, the everchanging demographic profile of families in Korea and other Asian countries calls for further attention to several important issues. I would like to discuss a few of them before concluding.

First, an increasing number of kinless and childless older adults calls for special attention. While only about 2 to 7% of current cohorts of Asian older adults are without children (Teerawichitchainan & Ha, forthcoming), future cohorts of older adults, with decreasing fertility rates, will have fewer or no children to help them when they are in need. If we consider those older adults who have children but cannot get any support from them because the children are either too far away to provide any instrumental support or are in strained relationships, the prevalence of childlessness will be greater (Teerawichitchainan & Ha, forthcoming). In traditional Asian culture, under norms of filial piety, adult children played an important role as sources of economic and instrumental support for older parents, and many Asian countries have developed social policies as supplements to family support (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001). However, with the increase in childless or kinless older adults, more and more people in the future will likely depend on social systems as their primary source of care. National strategies for dementia care should take this factor into account as they develop care systems, especially in rural communities where many younger generations out-migrate.

Second, although living with adult children or with a relative is still the most common living arrangement of older adults in most Asian countries (He et al., 2022), number of households that consist of older couples only is substantial, especially in East Asian countries (Lei, Strauss, Tian, & Zhao, 2015; Statistics Korea, 2023; Takagi, Silverstein, & Crimmins, 2007). Naturally, spouses are more likely to assume the role of the primary caregiver in these households when one of the spouses develops a serious health problem such as dementia. In South Korea, approximately 1/3 of informal caregivers (31.9%) of people with dementia are spousal caregivers (Ministry of Health and Welfare, 2011). Spousal caregivers are particularly vulnerable to mental and physical burden of caregiving for several reasons. First, many caregiving spouses are dealing with their own health problems, and the caregiving role can accelerate these problems (Schulz & Martire, 2004). Additionally, the changes in marital relationships induced by dementia may create psychological distress for spousal caregivers. As the dependence of persons with dementia on their spousal caregivers increases due to dementia, the reciprocity between spouses will likely decrease, and spousal caregivers may feel less supported by their spouse with dementia (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001). Couples also suffer reduced relationship quality as one partner’s cognitive impairment progresses (Lee, 2006). Consequently, spousal caregivers are susceptible to more depressive symptoms, greater financial and physical burden, and lower levels of psychological well-being than children and children-in-law caregivers (Hong and Kim 2008, Pinquart & Sörensen, 2011). In the case of Korea, many services are available for older adults who live alone, yet relatively little attention has been given to the families where one spouse is caring for the other or both spouses are caring for each other with much vulnerability. More policy attention should be given to these families.

Third, risk management in times of pandemic and natural disaster is becoming increasingly important in ensuring the well-being of older adults and families affected by dementia. During the past three years, we observed how Covid-19 had a more detrimental effect on older adults than on younger ones. Older people living in nursing homes, in particular, were exposed to a higher risk of infection and social isolation than the general population. Due to social distancing measures, nursing home residents became unable to eat with friends and participate in many of the programs provided within the facility. Above all, the ban on family visits led the residents of the nursing home to communicate with their families only through voice or video calls or outside the window from a distance. Older persons with reduced cognitive function or unfamiliar with video calling were not able to participate in such communications. Older persons with dementia are extremely vulnerable to these changes. They have difficulty understanding the rules such as social distancing, wearing a mask, and not going out. They can be puzzled and confused about why their family suddenly does not visit, why they have to stay in their rooms, and why caregivers all wear masks (Wan, 2020). Lack of exercise and decrease in cognitive stimulation due to social distancing can also negatively affect disease prognosis in older persons with dementia. Health care policies should acknowledge these unwanted consequences of social distancing during pandemics and develop creative measures to address these problems.

In conclusion, we have much to prepare as we foresee continued ageing of the population and changing social norms around elder care in Asian countries. Families and nations are to take shared responsibility of caring for older adults in order to enhance the quality of life and maintain the social integration of both care recipients and caregivers. With those shared efforts, we will be one step closer to reaching the SDG of ensuring healthy lives and promoting well-being for all at all ages.

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