

Addressing the challenges of dementia care

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Individuals living with dementia and their care partners often face numerous challenges that can lead to feelings of isolation. This article outlines how the Jockey Club Centre for Positive Ageing's crisis management hotline service has become a vital resource for supporting the wellbeing of those affected by dementia

Care partners of people with dementia face diverse challenges in their caring journey, often navigating crises stemming from the initial pursuit of a diagnosis to managing the complexities of daily care routines and planning long-term care. These responsibilities could profoundly impact the physical and psychological wellbeing of care partners, which, in turn, affects the care of people with dementia. The importance of providing adequate support for care partners has been increasingly emphasised, notably by the World Health Organization. ⁽¹⁾ Such support is vital for mitigating the negative impacts on care partners, ultimately contributing to better outcomes for individuals living with dementia and those who care for them.

Supporting carers through the Crisis Management Hotline Service

To address this pressing need, the Jockey Club Centre for Positive Ageing (JCCPA) established the Crisis Management Hotline Service for enquiries related to dementia care, thanks to a generous donation from private donor J. Shaw. This service aimed to assist care partners in navigating the complexities and crises of care by offering emotional support and connecting them with relevant community resources, providing critical crisis management during challenging moments. A trained practitioner was in charge of the service during office hours to address the concerns of care partners, provide emotional support, and offer advice on community resources. The evaluation on the effects of the service was conducted using a cross-sectional survey design, targeting care partners who utilised the hotline service between 2019 and 2024 to assess its impact on their knowledge, emotional wellbeing, and ability to access community support services.

A channel to voice concerns

The hotline service received more than 6,000 phone enquiries during the service period. More than three-quarters of these enquiries came from adult children or in-law care partners, and over 40% of the individuals they cared for were aged 80 or above. About half of the care partners lived with the persons they supported, and 47% identified themselves as the primary care partners. Three out of four care partner respondents reported that the care recipients had not received a formal dementia diagnosis, while care recipients who had a diagnosis were mainly in the early stage of dementia. Around 75%

of the care partners reported emotional stress due to the lack of understanding about dementia. They also encountered negative impacts on their personal wellbeing as the condition of the person they cared for deteriorated (19%), and expressed concern about the future progression of dementia (16%). The service users expressed the need to understand more about the diagnosis channel and progression of dementia, and community resources and services, while close to 40% of them sought advice on improving their caring skills.

The demographic profile of the service users aligns with the living arrangement in Hong Kong and other East Asian countries, where older adults often reside with their adult children. The cultural value of filial piety often places strong expectations on the younger generation to care for their parents, creating pressure for adult children to balance their caregiving role with work and other family responsibilities. ^(2,3)

Addressing anxieties around dementia care, symptoms and diagnosis

The high prevalence of undiagnosed cases resonates with the global estimates from Alzheimer's Disease International. ⁽⁴⁾ Diagnosis is often delayed or missed due to the complex and varied symptoms of dementia. They could be mistaken for other conditions, such as mood disorders, delirium, or urinary tract infection. ^(5,6)

The decline in cognition could be misattributed to normal ageing, leading to a delay or absence of the dementia diagnosis. This uncertainty in diagnosis could hinder access to essential medical and non-medical support services, intensifying the physical, emotional, social, and economic impacts on people living with dementia and their care partners. ^(7,8) This service served as a valuable resource to address the anxiety of care partners regarding diagnosis and facilitate timely diagnosis, which is crucial for providing appropriate care, planning, and support, ultimately improving the quality of life for people with dementia and their care partners.

The lack of knowledge and skills in care could lead to frustration and exhaustion for care partners. When they are unable to provide appropriate care, it not only impacts the quality of life for their loved ones but could also accelerate their stress and anxieties about the future. Accessing relevant information can be challenging for care partners, as they may be unsure where to find reliable resources or be unaware that support services exist. The hotline service plays a crucial role in addressing this need by serving as an information provider. By providing knowledge and connecting care partners with appropriate support, the service empowered them to deliver better care and enhance their physical and psychological wellbeing.

To further address the challenges of undiagnosed dementia and the impact of care, JCCPA has launched the territory-wide Jockey Club 'Brain Health' Dementia Screening and Community Support Project with the generous support of The Hong Kong Jockey Club Charities Trust. Guided by the principle of 'early detection, early diagnosis, and early intervention,' individuals suspected of cognitive impairment conduct a validated electronic cognitive screening test at home. Participants will be referred to the organisations in their

local communities and programme doctors for further follow-up if needed. Subsidised medical services, including medical consultations, health checks, brain scans, and blood tests, are provided to encourage early diagnosis.

To conclude, the Crisis Management Hotline Service has proven to be a vital resource for care partners of individuals with dementia. By addressing critical needs during crisis moments, the service effectively delivered emotional support, enhanced knowledge about dementia diagnosis and progression, and facilitated access to community resources. Coupled with the Jockey Club's 'Brain Health' Dementia Screening and Community Support Project, these initiatives promote early detection, timely diagnosis, and comprehensive support, ultimately improving the quality of life for people with dementia and their care partners.

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