

Eldercare Hong Kong

Working dementia caregivers: Challenges and Needs

Full Report 2020



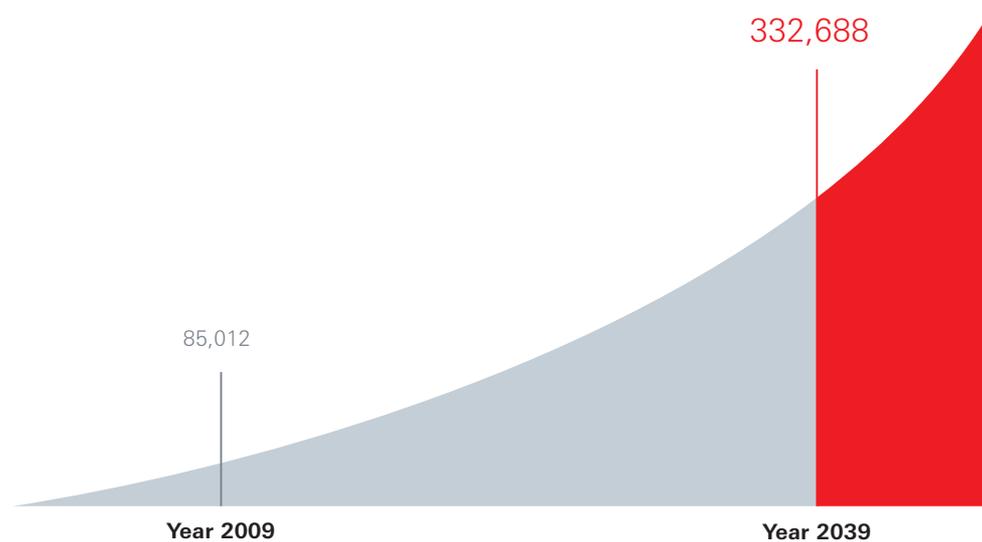
Contents

Introduction	02
Working dementia caregivers' portfolio	04
Key findings and recommendations	05
▪ Financial stability	05
▪ Support network	07
▪ Mental healthiness	09
▪ Information accessibility	11
Conclusion	13
Reference sources and disclaimer	14

Introduction

According to a recent study, the number of people in Hong Kong with dementia aged 60 or above was 85,012 in 2009 and is projected to reach 332,688 by 2039¹.

Number of people in Hong Kong with dementia (aged 60 or above)



In view of the current demand for dementia caregiving in society, HSBC Life (International) Limited (“HSBC Life”), together with the Sau Po Centre on Ageing at The University of Hong Kong and The Women’s Foundation, produced a study: “Working dementia caregivers: Challenges and Needs” (“Study”). This Study conducted both quantitative and qualitative research methods to understand the care challenges and needs of people who are in paid employment as well as in unpaid caregiving responsibilities for their demented family members simultaneously. Such people are referred to as “working dementia caregivers”. The research looked at issues faced by these caregivers including financial stability, support network, mental healthiness and information accessibility with a gender-specific lens.

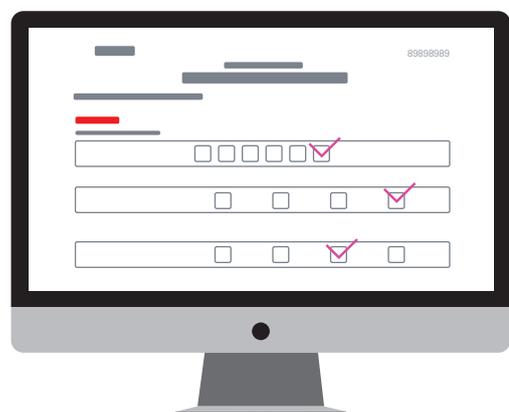
Qualitative:

Two focus groups with 17 working dementia caregivers.



Quantitative:

Online survey with 171 working dementia caregivers.



**Edward Moncreiffe**

Hong Kong Chief Executive Officer,
HSBC Life (International) Limited

“In Hong Kong, the number of people aged 60 or above is projected to quadruple from 2009 to 2039¹. Coupled with the increasing prevalence of dementia which often can last from 6 to well over 20 years², an increasing number of older adults will require regular unpaid care or support, mostly from family caregiving. Apart from the financial and societal impact on the community, we are equally if not more concerned about the physical and psychological well-being of working dementia caregivers who are simultaneously subjected to an enormous financial and employment impact. Through the Study, we aim to consolidate and recommend best practices in supporting dementia caregivers that encompass the key areas of financial stability, support network, mental healthiness and information accessibility in a holistic way.”

**Dr. Vivian Lou**

Director, Sau Po Centre on Ageing,
The University of Hong Kong

“In the process of creating a caregiver-friendly society, an innovative bottom-up gender-responsive model needs to be adopted to provide practical solutions. For the society as a whole, it is critical to look into the caregiver spectrum. We also advocate the establishment of a 24/7 one-stop online platform that allows caregivers to obtain a comprehensive and centralised resource map. In addition, caregivers are encouraged to actively enhance and share care literacy, so as to build a learning community for caregivers.”

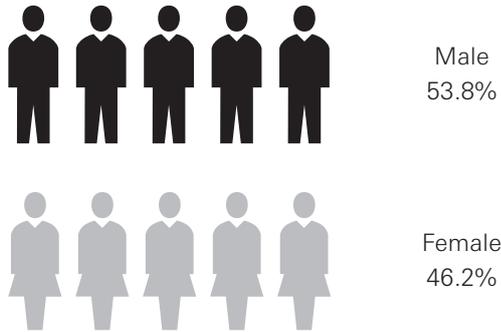
**Fiona Nott**

Chief Executive Officer,
The Women’s Foundation

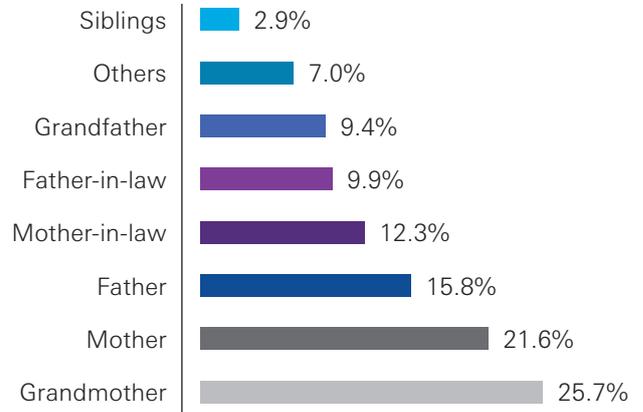
“The stress felt by working dementia caregivers is deeply concerning and we must take action to provide them with better support through a gender-specific lens. Traditional gender roles – with men seen as primary earners and women as primary carers – affect how caregivers perceive the stress they are feeling, and these differences must inform our policies and services to help them. Urgent action is needed from the Government and employers to broadly support working dementia caregivers. For these policies and services to be effective and fully utilised by both men and women, they must be created and implemented with a gender-sensitive approach.”

Working dementia caregivers' portfolio

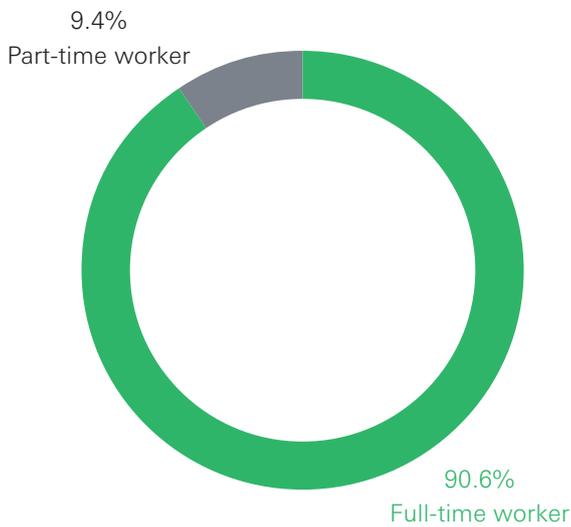
Gender of working dementia caregivers
(Total number=171)



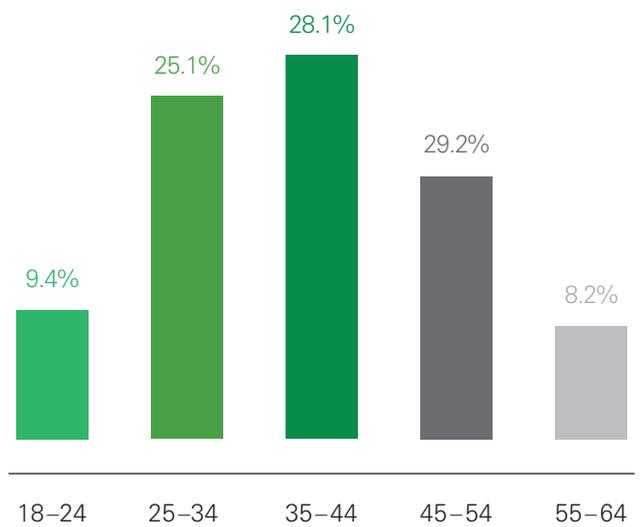
Relationship with care recipients
(Total number=171)



Employment status of dementia caregivers
(Total number=171)



Age group of working dementia caregivers
(Total number=171)



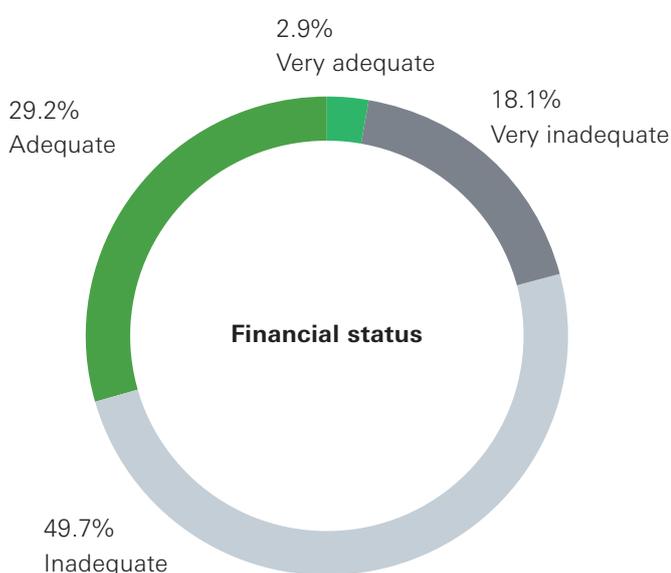
Key findings and recommendations

Financial stability

More than two-thirds of working dementia caregivers reported that the financial status of their care recipients was inadequate.

When asked about their care recipients' financial status, more than two-thirds (67.8%) of caregivers reported that it was inadequate or very inadequate. The care recipients' sources of income were diversified, with the top three as follows: family support (52.6%), Old Age Living Allowance (46.8%), and savings (40.9%). Only 15.8% of them were covered by insurance.

Care recipients' perceived financial status

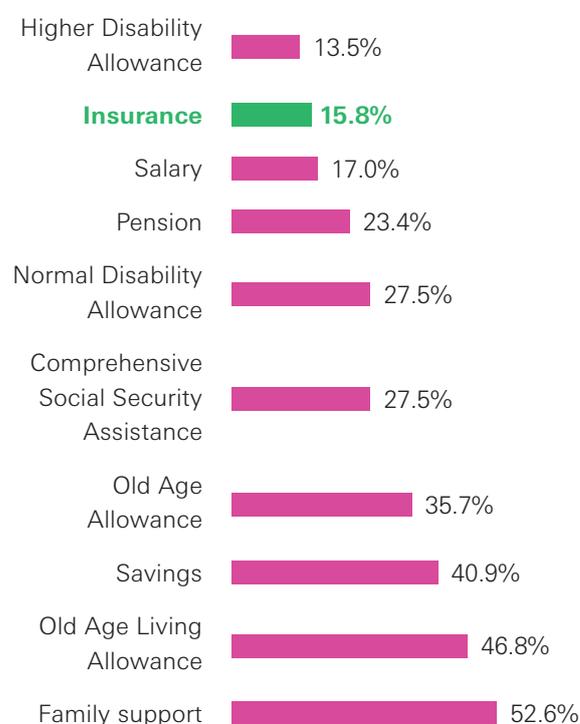


67.8%

of respondents perceived that their care recipients do not have adequate financial resources



Care recipients' sources of income



Feedback from focus groups

Is there any insurance or investment that the general public can opt for to better prepare for the future? I think financial planning is important, especially when caregivers will become fewer while the number of dementia patients will rise.



Financial stability recommendations

Life-course perspective on financial planning

It is important to raise public awareness about the cost of dementia caregiving as well as general eldercare costs. Early financial and retirement planning is essential to provide a safety net for both potential caregivers as well as their care recipients. Even among working adults that do not become future caregivers, early financial and retirement planning can protect them from poverty. This is an area where the Government, employers, NGOs and the insurance industry can all contribute.



The Government may collaborate with NGOs and other relevant organisations to promote public campaigns and provide public education workshops/training around understanding the financial challenges of working dementia caregivers, and offer financial planning for caregivers, particularly paying attention to segments of the population that may have less existing knowledge. The Government could also provide assistance, such as:

▶ **Enact legislation to protect working caregivers**

The Government may consider enacting legislation to protect working caregivers. Such legislation would cover care and income security needs, including flexible working arrangements, social assistance, allowances or wages, tax relief and ensure explicit protection (including income and MPF) for caregivers; and

▶ **Implement a societal income insurance mechanism that protects the income of caregivers who need to take a partial/complete break from work to provide caregiving**

The Government, working closely with the private sector and insurance industry, may explore the possibility of a public-private scheme or set of insurance products that would enable companies and/or individuals to have the option of income protection in the event the employee needs to move to part-time hours or stop work due to caregiving responsibilities. This would ensure that individuals continue their MPF contributions, thus help alleviate financial pressure.



Employers can provide training and support for employees with future dementia caregiving responsibilities to educate themselves, such as how to integrate financial planning for ageing dependents into personal financial plans and household budget management.



The insurance industry should act collectively and take the lead in raising awareness about the cost of caregiving. It is recommended that the industry should provide structured financial planning workshops and innovative products.

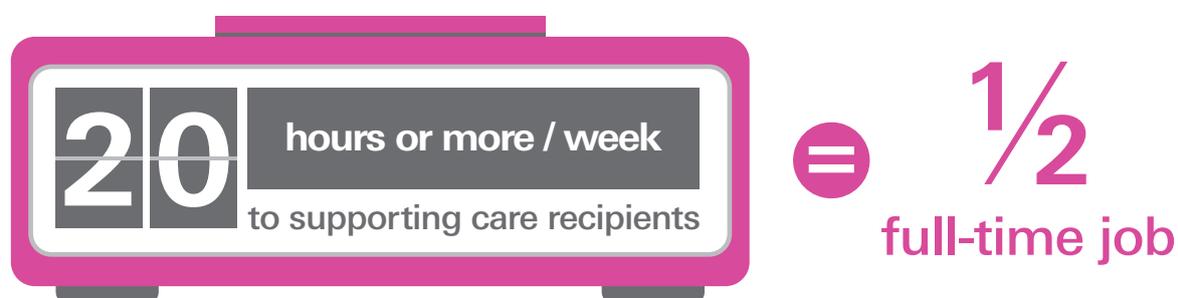


Support network

Working dementia caregivers lack a support network.

Attention should be drawn to the fact that 35.7% of working dementia caregivers were providing more than 20 hours of caregiving per week, an amount similar to a part-time job, leaving little time for socialising or self-care.

35.7% of respondents devoted



Feedback from focus groups

I do think that I was working for two different jobs, one in the workplace and the other at home. I would like to have some respite service, so I can “breathe” and not worry about letting my mother (care recipient) stay at home alone.



Support network recommendations



Increase the quota for respite services

The Government is recommended to review existing services and provide more quotas for both day and residential respite services. Respite care can help to relieve the responsibility of providing care, allowing caregivers to recharge and continue with their caregiving role.

Establish volunteer networks in the community

The Government and private sector may consider setting up volunteer networks that provide home visits to dementia patients, which would enable caregivers to have some time for themselves to balance between their jobs, social life and caregiving tasks.

Workplace accommodative measures

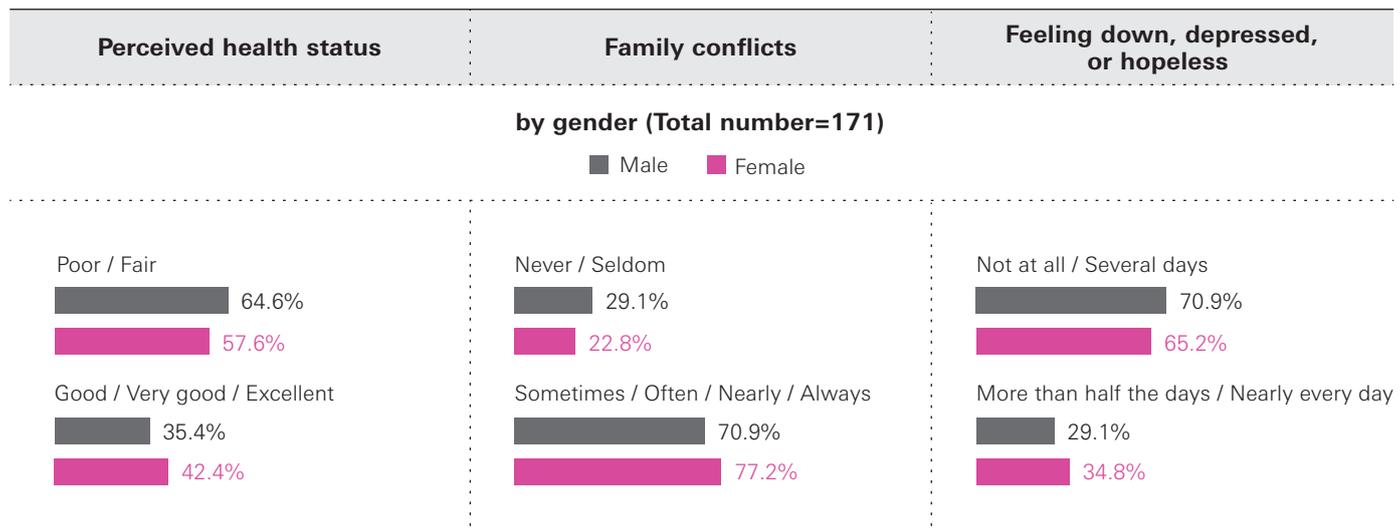
Taking care of a dementia patient can be challenging and time consuming. It is recommended that employers consider providing workplace accommodative measures to employees, which can include:

- ▶ **Needs assessments:** Conducting periodic company-wide assessments/surveys to identify the needs of employees with eldercare responsibilities;
- ▶ **Business awareness:** Being aware of the strong business case for policies and initiatives that support a diverse and inclusive awareness including caregivers, which leads to higher productivity, staff recruitment and retention, job satisfaction and reduced stress;
- ▶ **Compassionate caregivers' leave:** Providing paid time off for caring obligations include annual paid caregivers' leave; compassionate caregivers' leave, and/or emergency time off;
- ▶ **Manager training:** Training managers and supervisors to be more supportive of employees with eldercare responsibilities; and
- ▶ **Support networks:** Creating and championing internal caregiver support networks.

Mental healthiness

Higher risk for dementia caregivers related to their physical and psychological needs.

Study findings showed around two-thirds (64.6%) of male working dementia caregivers perceived their health status as poor or fair. For female working caregivers, around 57.6% perceived their health status as poor or fair, while around one-third (32.6%) reported good, and the remaining 9.8% reported very good, with none reporting excellent. Working dementia caregivers also reported family conflicts and feeling down, depressed, or hopeless.



Feedback from focus groups

I suggest that caregivers seek professional help from counsellors if needed.



Mental healthiness recommendations

Raise public awareness on dementia caregiving

It is important to raise public awareness on the adverse mental health effects of dementia caregiving. It is only with a more collective understanding of this disease that people in society can help each other and face the challenges.



Increase professionals' sensitivity towards caregivers' needs

Healthcare and social care service providers should review existing services and consider a care management approach when providing dementia care services, which includes providing quality services to patients and caregivers. Structural training and protocol guidance for professionals are needed to increase their sensitivity towards dementia caregivers.

Increased public awareness and accessibility of mental health services

The Government, together with NGOs and other relevant organisations, may promote public campaigns on taking care of mental health and encouraging self-care among caregivers. The Government may also consider providing more funding to mental health services. Employers can consider providing their employees with information, training or programmes around strategies to care for one's mental health while providing caregiving.

Understanding Behavioural and Psychological Symptoms of Dementia (BPSD)

Local institutions, NGOs and the Government are recommended to consider offering systematic courses on Behavioural and Psychological Symptoms of Dementia (BPSD) associated with dementia patients. It is necessary for dementia caregivers to equip themselves with knowledge of the disease and develop effective management strategies.

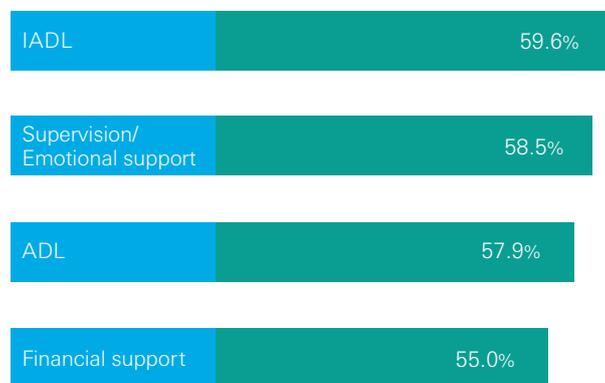


Information accessibility

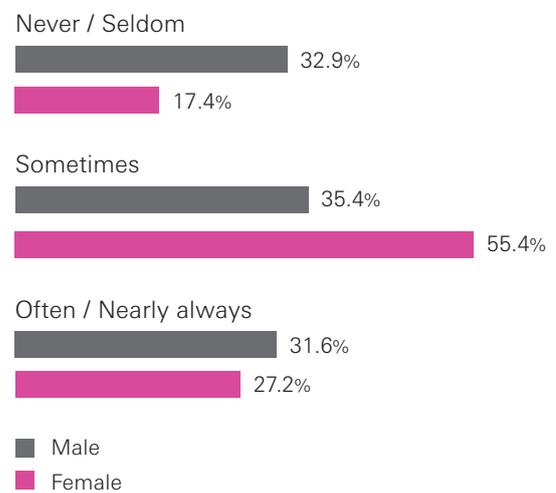
Dual roles* of working dementia caregivers.

Around 59.6% of the respondents reported that they provided assistance in Instrumental Activities of Daily Living (IADL³), such as shopping, preparing meals, and taking medications. Nearly 58.5% of the respondents provided supervision/emotional support to their care recipients, while 57.9% provided assistance in Activities of Daily Living (ADL⁴), such as eating, walking, and bathing. Additionally, around 55% provided financial support, which is consistent with the findings regarding care recipients' sources of income. Fulfilling the dual roles of working dementia caregivers demand extensive time and resources.

Caregiving tasks of working dementia caregivers (Total number=171)



Lack of time for self by gender (Total number=171)



Feedback from focus groups

I feel that there is a pressing need for the Government to provide a one-stop online platform for us (dementia caregivers), so we can search for resources in an organised and systematic way.



* 'Dual roles' refers to an individual's responsibility to engage in both paid employment and unpaid care work

Information accessibility recommendations



One-stop online resources platform for working dementia caregivers

The Government is recommended to consolidate community resources and create a user-friendly, one-stop online resources platform for dementia caregivers. It is important to support caregivers in searching for information and resources which could ease their burden. To enable caregivers to access resources in a timely manner, we recommend building a resources map on the platform.

Resource corner in the workplace

Employers are recommended as follows:

- ▶ Consider setting up a resource corner for employees with caregiving needs, providing useful dementia knowledge and community resources. Knowledge enhancement workshops and talks can also be provided to equip employees with caregiving knowledge and raise their awareness of early dementia symptoms. Actions can include:



Open discussions:

Institute regular open discussions about non-work family issues which makes it permissible to talk about eldercare and facilitate flexible working among teams;



Champions:

Identify leaders to champion a caregiver-friendly workplace culture; and



Employee Assistance Programmes:

Consider providing a one-stop service, often called Employee Assistance Programmes. These can include access to expert advice on what to do in a crisis, vetting and advising on medical care options, booking assisted living facilities, identifying at-home support, and other logistical and/or legal advice.

Conclusion



Public-private collaborations and partnerships needed to address challenges for working dementia caregivers

The Study's findings indicate that working caregivers face challenges in 4 aspects, including financial stability, support network, mental healthiness and information accessibility. It is important that all sectors take a forward-looking and long-term, sustainable approach to tackle the challenges that confront working dementia caregivers, balancing the current needs with future needs of working dementia caregivers and care recipients. Public-private partnerships are critical for our economy and workplaces. As individuals, it is important that as the number of working caregivers will increase, they will stay in the workforce as long as possible while still meeting the needs of their care recipients. To ensure a working caregiver-friendly environment, it is vital that all sectors work together to creatively and holistically address the short- and long-term needs of working dementia caregivers.

Reference sources

1. Yu, R., Chau, P. H., McGhee, S. M., Cheung, W. L., Chan, K. C., Cheung, S. H., & Woo, J. (2012). Trends in Prevalence and Mortality of Dementia in Elderly Hong Kong Population: Projections, Disease Burden, and Implications for Long-Term Care. *International Journal of Alzheimer's Disease*, 2012, 1-6. doi:10.1155/2012/406852.
2. Gilbert, 2019; World Health Organisation, 2020.
3. Instrumental Activities of Daily Living (IADL) include shopping, preparing meals and taking medications.
4. Activities of Daily Living (ADL) include eating, walking and bathing.

Disclaimer

HSBC Life and HSBC Group shall not be liable for any information relating to the Study on “Working dementia caregivers: Challenges and Needs” in this report.