



MINISTRY OF HEALTH MALAYSIA
INSTITUTE FOR HEALTH SYSTEMS RESEARCH



The **IMPACT** of caregiving intensity on informal caregivers in Malaysia: findings from a national survey

Juhana Lawahir

Asian Family Conference 2024

Marina Bay Sands Expo & Convention Centre, Singapore



OUTLINE OF PRESENTATION

INTRODUCTION

- Informal caregiver
- Context of Malaysia
- Impact of caregiving intensity role

OBJECTIVES

METHODOLOGY

- National Health and Morbidity Survey
- Instrument
- Designs and participants
- Statistical analysis

KEY FINDINGS & DISCUSSION

RECOMMENDATIONS ON POLICY

AND PRACTICE





INFORMAL CARE

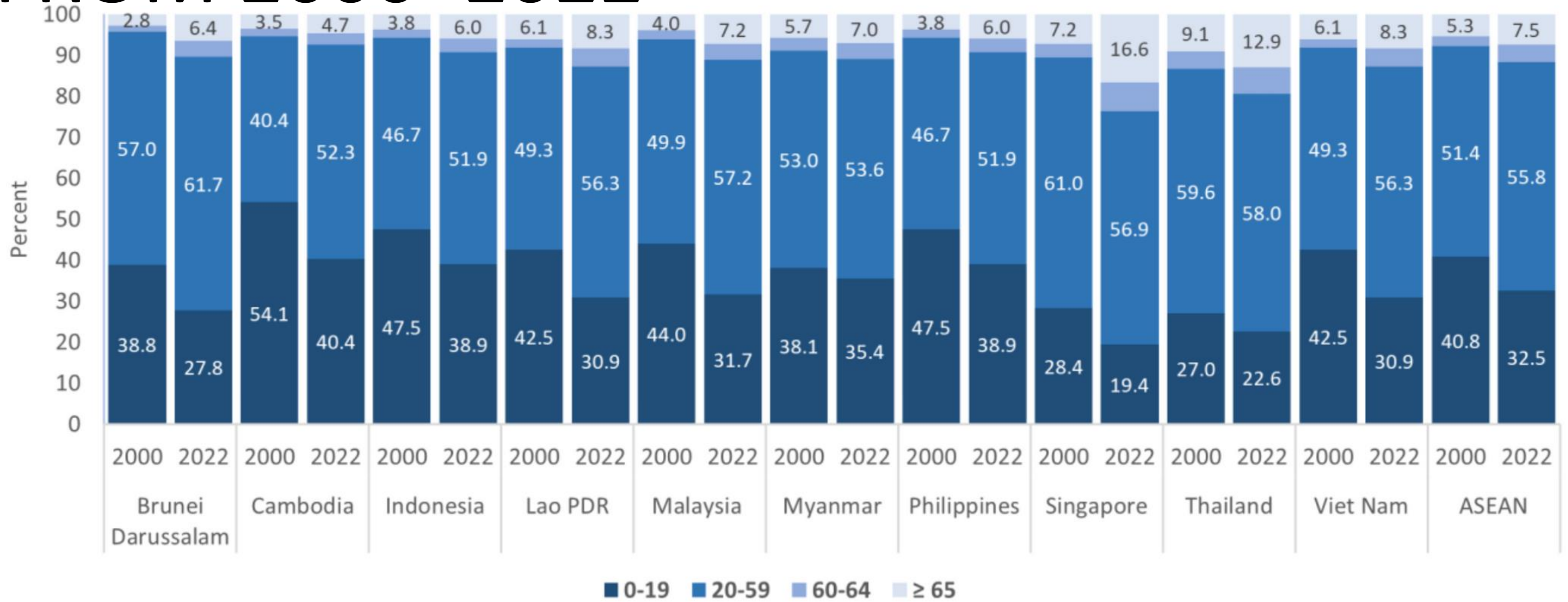
Informal care is defined as the **provision of unpaid care or assistance** with activities of daily living, to individuals **who need help**, due to **chronic health conditions, disability or old age** [1].

Excludes care provided by professionals or through organised volunteer services [2].

Care provided includes **personal care, healthcare, and other assistance** [3].

Ref: [1] Colombo F, Mercier J. Help wanted? Fair and sustainable financing of long-term care services. *Appl Econ Perspect Policy*. 2012;34(2):316–32; [2] Broese van Groenou MI, De Boer A. Providing informal care in a changing society. *Eur J Ageing*. 2016;13:271–9; [3] Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, National Academies of Sciences, Engineering and M. Families caring for an aging America. Washington (DC): National Academies Press (US); 2016.

ASEAN'S DEMOGRAPHIC TRENDS FROM 2000–2022



The demographic trend has shifted with the **percentage of the elderly people (aged 65+) increasing** over the past two decades in ASEAN countries [1].

Ref: [1] ASEANstats. ASEAN Statistical Brief [Internet]. Vol 3 (December 2023); 2023. Available at: <https://www.aseanstats.org/publication/asb202312>

CONTEXT OF MALAYSIA

Malaysia's demographic structure has **shifted towards an ageing population** [1].

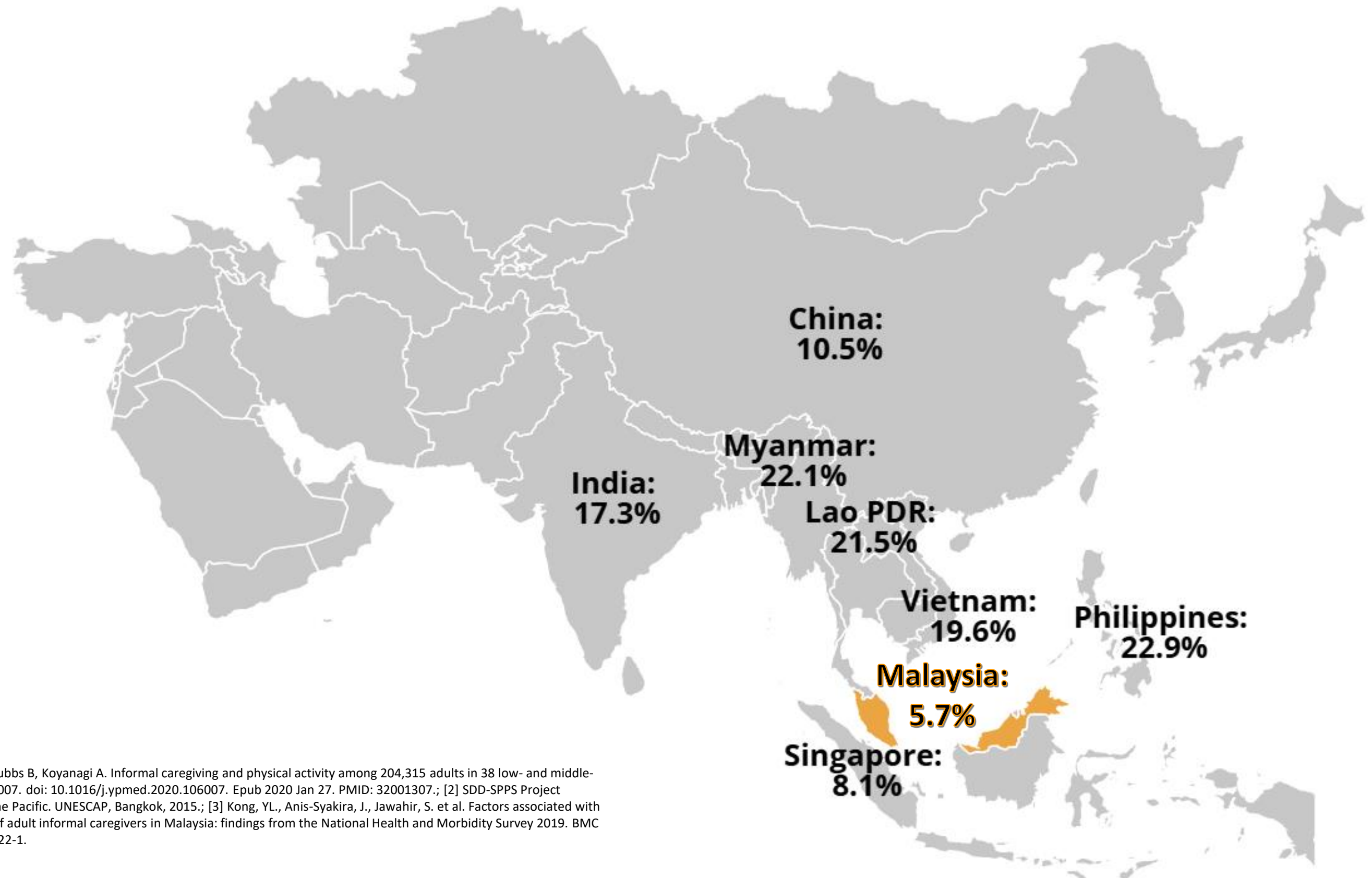
The ageing population along with the rise in incidence of chronic and degenerative diseases - points towards an **increased need** for informal care provision [2].

Family or friends - first line of support for informal care, as **cultural values and norms** pertaining to perceived family obligation influence people to care for their next-of-kin [3-5].

Ref: [1] ASEANstats. ASEAN Statistical Brief [Internet]. Vol 3 (December 2023); 2023. Available at: <https://www.aseanstats.org/publication/asb202312>; [2] Hayashi R. Demand and supply for long-term Care for Older Persons in Asia; 2019; [3] Broese van Groenou MI, De Boer A. Providing informal care in a changing society. *Eur J Ageing*. 2016;13:271-9; [4] Abu Bakar SH, Weatherley R, Omar N, Abdullah F, Mohamad Aun NS. Projecting social support needs of informal caregivers in Malaysia. *Heal Soc Care Community*. 2014;22(2):144-54; [5] Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annu Rev Psychol*. 2020;71(1):635-59.

PREVALENCE OF INFORMAL CAREGIVERS

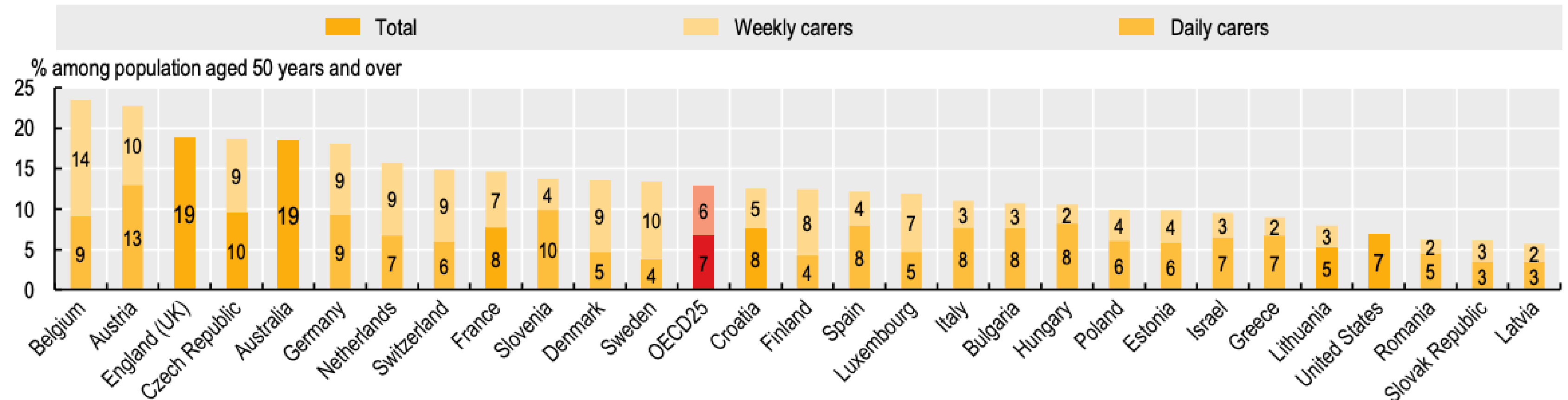
Overall, the prevalence of informal caregivers in Malaysia (5.7% of the adult population) was low as compared to other Asian countries.



Ref: [1] Jacob L, Smith L, Jackson SE, Shin JI, Haro JM, Vancampfort D, Stubbs B, Koyanagi A. Informal caregiving and physical activity among 204,315 adults in 38 low- and middle-income countries: A cross-sectional study. *Prev Med.* 2020 Mar;132:106007. doi: 10.1016/j.ypmed.2020.106007. Epub 2020 Jan 27. PMID: 32001307.; [2] SDD-SPPS Project Working Papers Series: Long-Term Care For Older Persons In Asia And The Pacific. UNESCAP, Bangkok, 2015.; [3] Kong, YL., Anis-Syakira, J., Jawahir, S. et al. Factors associated with informal caregiving and its effects on health, work, and social activities of adult informal caregivers in Malaysia: findings from the National Health and Morbidity Survey 2019. *BMC Public Health* 21, 1033 (2021). <https://doi.org/10.1186/s12889-021-11022-1>.

PREVALENCE OF INFORMAL CAREGIVERS AMONG THE POPULATION AGED 50+

Figure 10.15. Share of informal carers among the population aged 50 and over, 2019 (or nearest year)



Note: The definition of informal carers differs between surveys (see the “Definition and comparability” box).

Source: SHARE, wave 8 (2019-20); SDAC (2018) for Australia; ELSA, wave 9 (2018-19) for the United Kingdom; HRS, wave 14 (2018-19) for the United States.

- Malaysia : 4.3% (95% CI: 3.6-5.1) (NHMS 2019) [2].

Contents lists available at ScienceDirect

Health Policy

journal homepage: www.elsevier.com/locate/healthpol




Ref: [1] OECD (2023), Health at a Glance 2023: OECD Indicators, OECD Publishing, Paris, <https://doi.org/10.1787/7a7afb35-en>; [2] Author’s own analysis using NHMS 2019 data.; [3] Courtin E, Jemai N, Mossialos E. Mapping support policies for informal carers across the European Union. Health Policy. 2014 Oct;118(1):84-94. doi: 10.1016/j.healthpol.2014.07.013. Epub 2014 Aug 1. PMID: 25132460.

Review

Mapping support policies for informal carers across the European Union

Emilie Courtin*, Nadia Jemai, Elias Mossialos

LSE Health and Social Care, London School of Economics and Political Science, London, UK





ECONOMICS

Sociology

Samsudin, S., Abdullah, N., Ismail, N. S. A., Hassan, K., & Ahmad, U. A. (2019). Growing old at own home: A study among pre-elderly adults in Peninsular Malaysia. *Economics and Sociology*, 12(1), 115-124. doi:10.14254/2071-789X.2019/12-1/6

GROWING OLD AT OWN HOME: A STUDY AMONG PRE-ELDERLY ADULTS IN PENINSULAR MALAYSIA

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ABSTRACT. The study of changes and choices of living arrangements among older persons has been a key element of demography and sociology of the family. While many studies focus on the elderly respondents in understanding this matter, our aim is to seek answers from the pre-elderly adults concerning their preferred old-age living arrangements and analyse the factors affecting the choice. A multistage sampling technique was used in selecting the respondents aged 40 to 59 years from Peninsular Malaysia. The total of 1,153 respondents were interviewed face-to-face using a structured questionnaire and it was found that 83.8% of the respondents prefer growing old in their own homes. From the probit model, it suggests that age and household size have negatively influenced the likelihood of the elderly to live in their own homes while being a male has the opposite effect. Those who are married or divorced, at work, earn more than RM15,000 a month and have formal education are more likely to prefer to grow old in their own homes as compared to other alternatives. Understand the choices of the pre-elderly groups are deemed vital for early intervention. A comprehensive support system is needed to endorse the popular choice of independent living at old age.



Are we ready for an ageing society?

Are we prepared to meet the growing needs

of our older population,
especially when it comes to

OBJECTIVES

1

Determine the **characteristics of caregivers** based on **care intensity** level

2

Examine the **predictive factors** associated with the **effects of caregiving roles on health, daily and social activities** of informal caregivers providing a **low-intensity level of care**

3

Examine the **predictive factors** associated with the **effects of caregiving roles on health, daily and social activities** of informal caregivers providing a **high-intensity level of care**.

METHODOL OGY

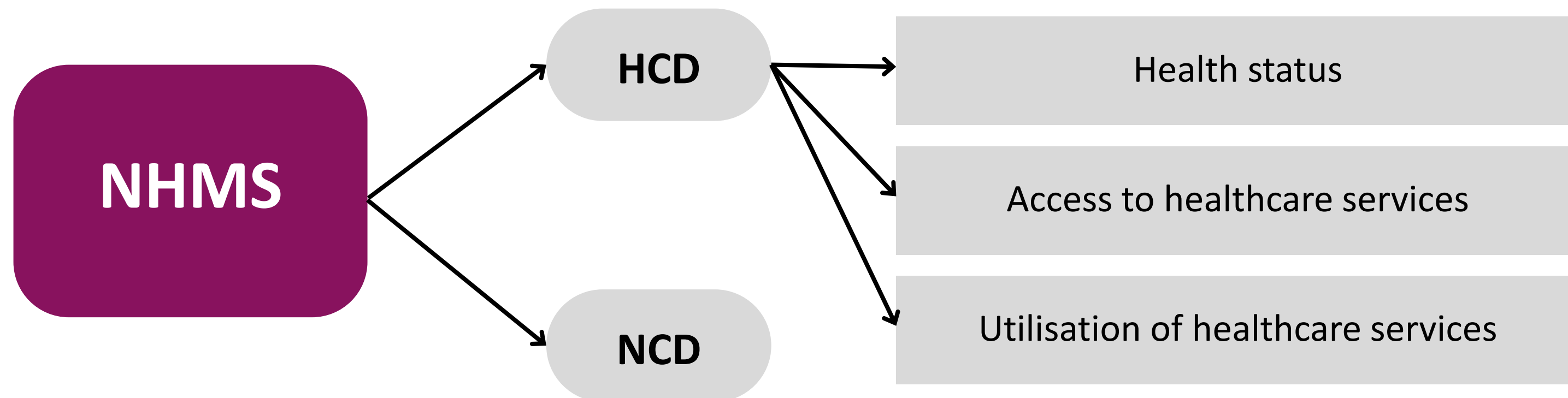


NATIONAL HEALTH AND MORBIDITY

SURVEY

The **National Health and Morbidity Survey** (NHMS) is a nationwide population-based cross-sectional survey that provides information on Malaysia's disease burden, health problems, health needs, and health expenditures.

Healthcare Demand (HCD) module is an integral part of NHMS for the last 4 decades.



The informal care module was introduced for the first time in the NHMS 2019 survey.

METHODOL OGY

“In the last 12 months, from ... 2018 till today, did you **provide care to ... with long-term illness, elderly or disabled?**”

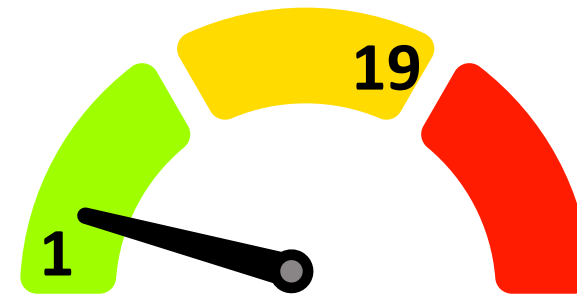
- your **household member or other than your household member**
- care that was provided for **at least 3 months**
- **did not involve wage or salary**, community service or volunteer activity.

METHODOL OGY

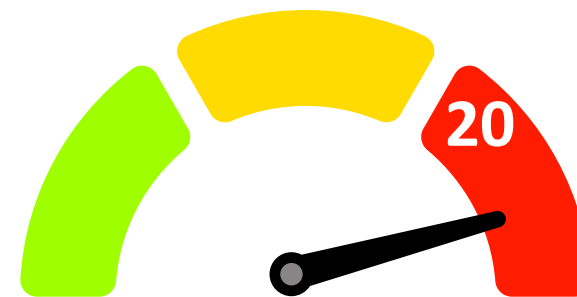
Level of **intensity of care** was assessed by the question “In total, **how many hours per week** did you normally spend providing care to the care recipient?”

The number of caregiving hours was then grouped into **two categories**:

- **low-intensity: 1–19 hours**



- **high-intensity: 20+ hours**



METHODOLOGY

Effects of caregiving roles on health, daily and social activities

The respondents were asked to answer “yes” or “no” to the following questions:

- Have your role in providing care affected your health (physical and/or mental health)?
- Have your role in providing care affected your daily, work or school activities?
- Have your role in providing care affected your social activities and others?

METHODOL OGY

Data of **adults aged 18 years and over** from the National Health and Morbidity Survey 2019 were used.

Respondent's demographic, socioeconomic, health, and caregiving-related characteristics were described using **complex sample analysis**.

Logistic regression analysis was performed to examine the predictive factors affecting health, daily and social activities of caregivers, accounting for caregiving intensity.

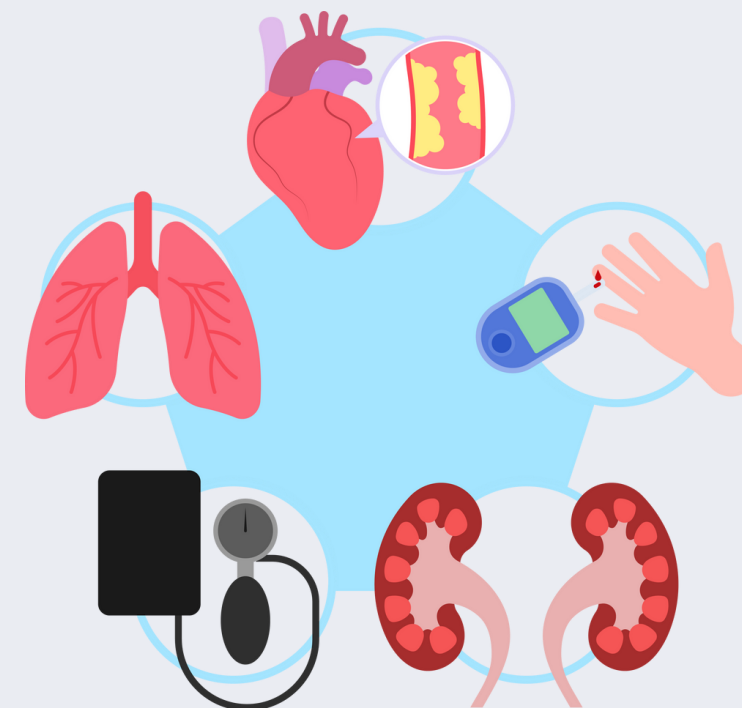
KEY FINDINGS & DISCUSSION



The average number of hours spent on caregiving per week:

24.8
hours/week

Type of care provided:



Healthcare

87.7%



Personal care

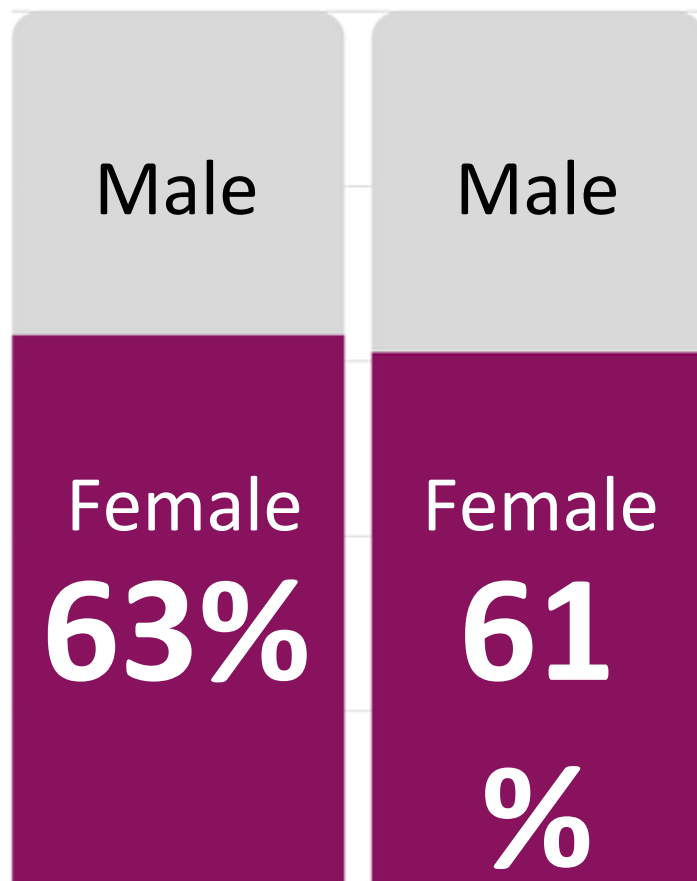
79.8%



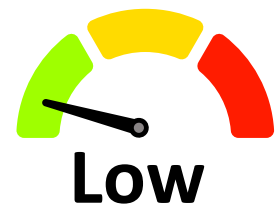
Others

1.5%

• Sex

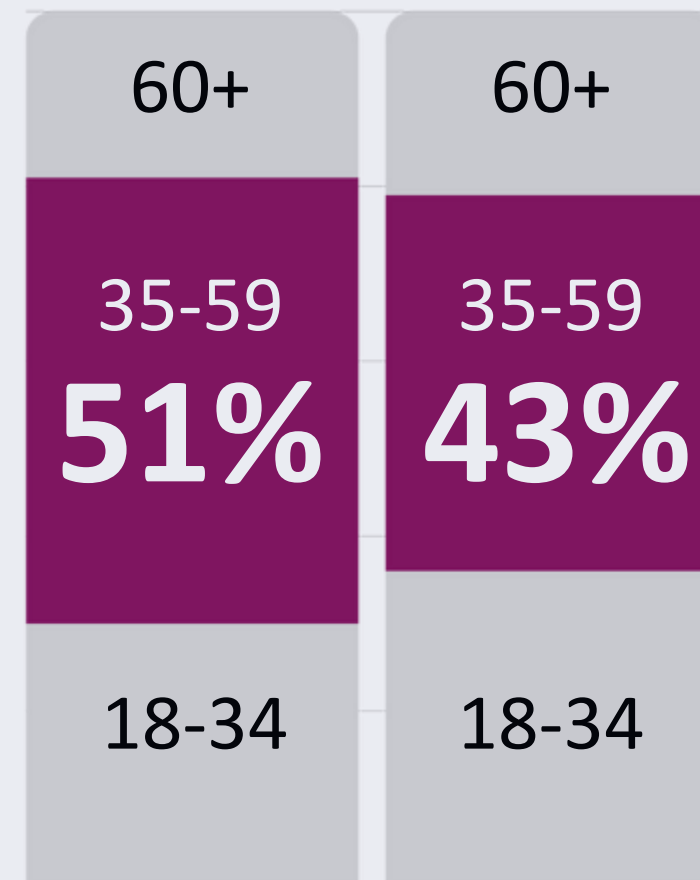


Almost
of informal caregivers
are **female**

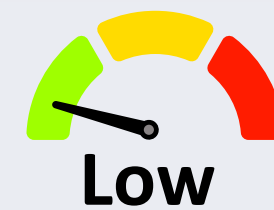


Note: Low = low-intensity caregiver; High = high-intensity caregiver

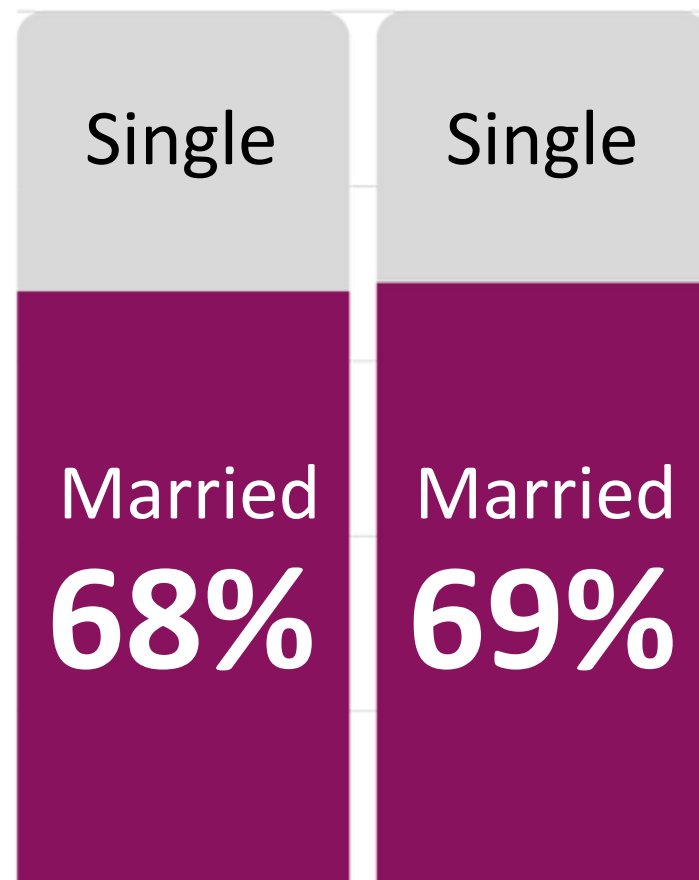
• Age



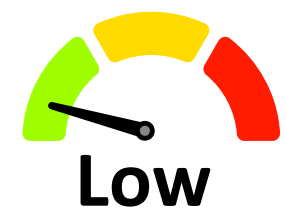
of informal caregivers
are **middle-aged adults**



- **Marital status**

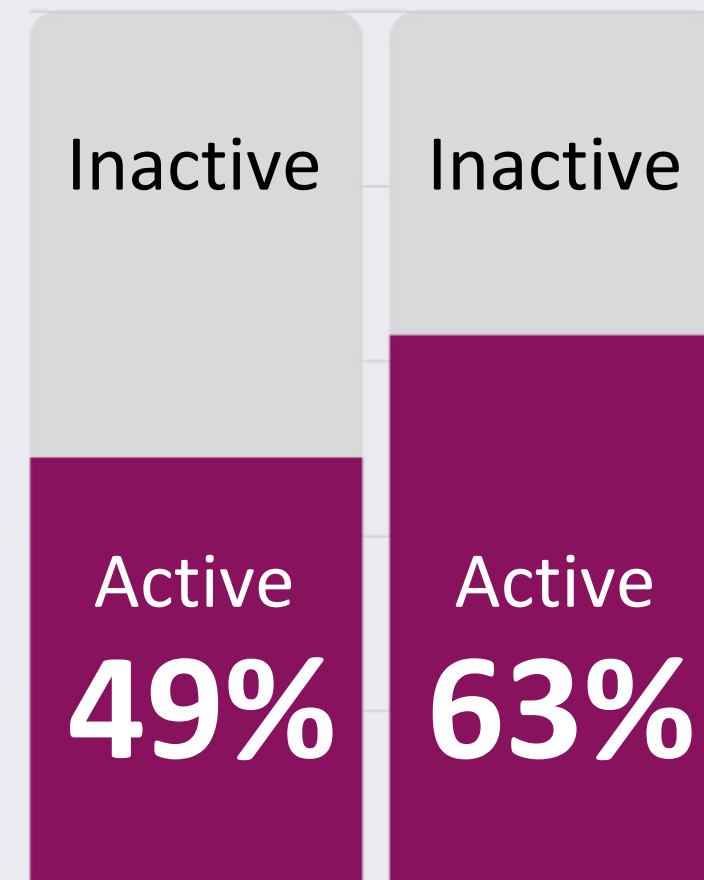


of informal caregivers are **married**




Note: Low = low-intensity caregiver; High = high-intensity caregiver

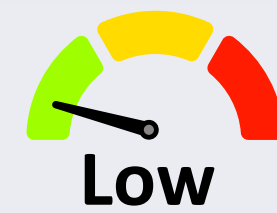
- **Employment status**



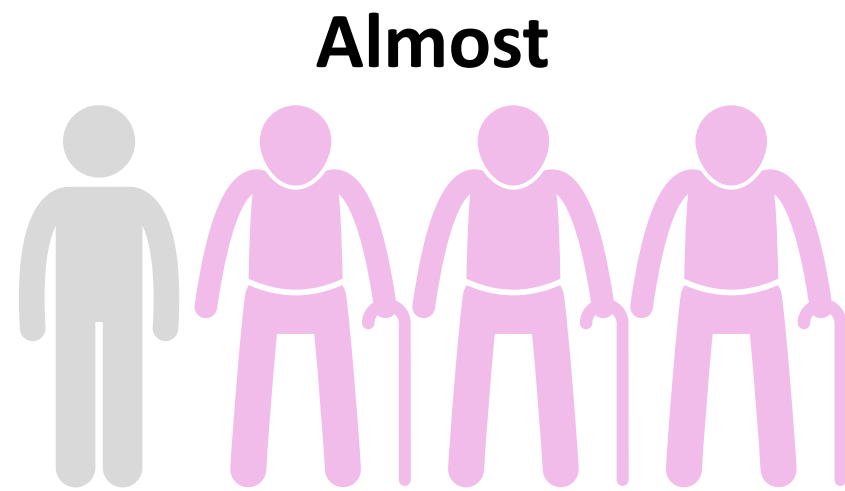
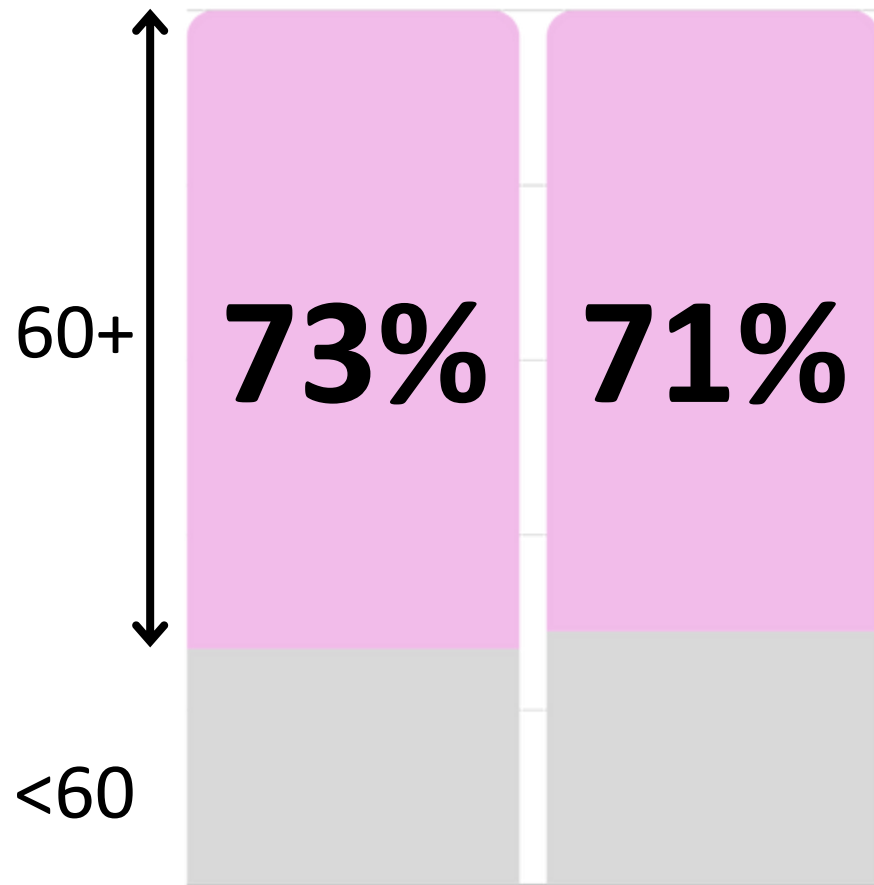
At least



of informal caregivers are **employed**

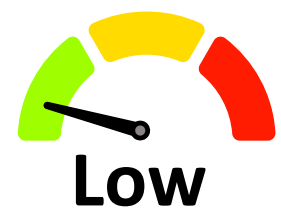


- Age



of informal care recipients are **older adults**

Mean age = 64.1
(Q1 = 57, Q3 = 80)



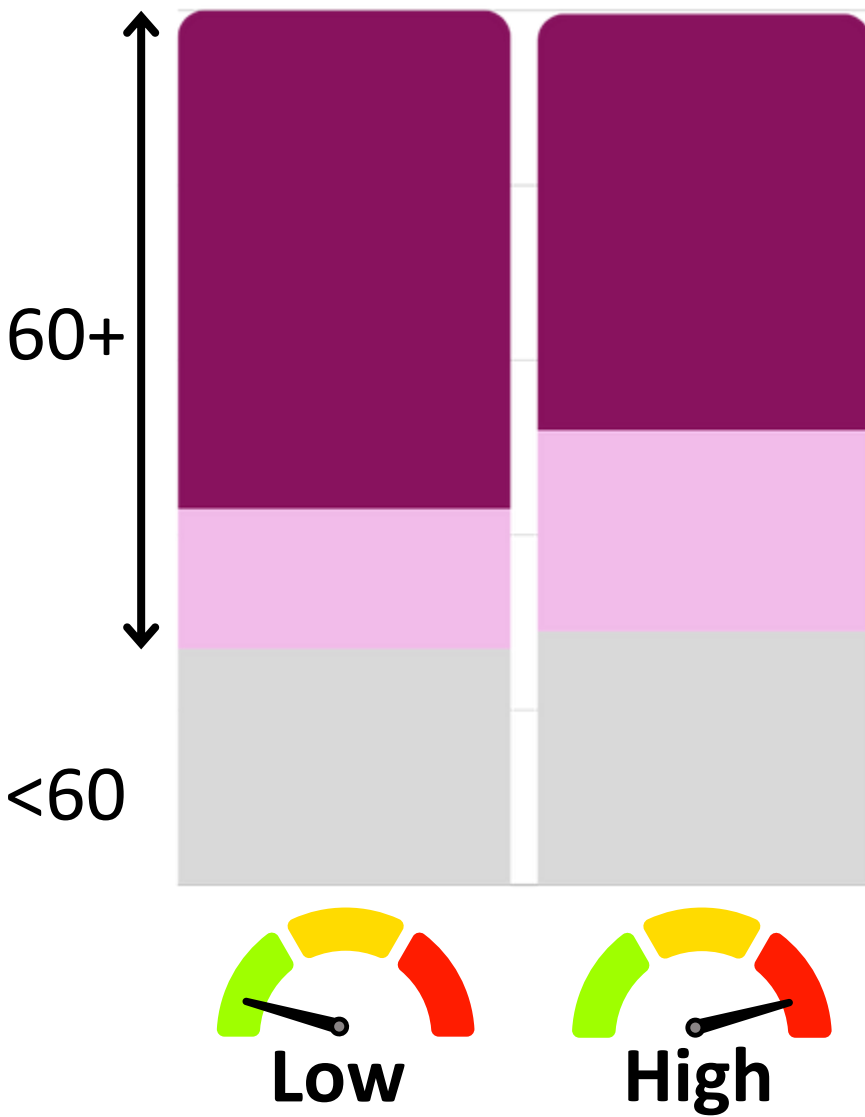
Note: Low = low-intensity caregiver; High = high-intensity caregiver



KEY

FINDINGS

Older adults caring for the older adults?



At least

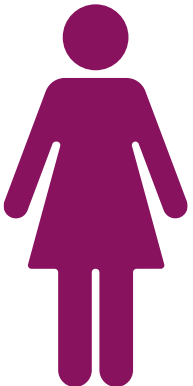
of older care recipients received informal care from the older caregivers.



Note: Low = low-intensity caregiver; High = high-intensity caregiver

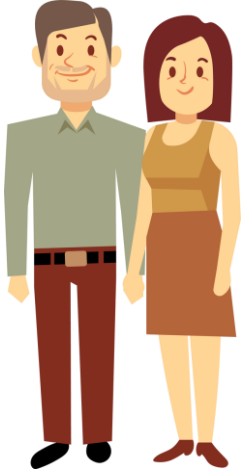
KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
Low



3 times more likely

Female



4 times more likely

Middle aged
adults

to have had their **health impacted.**



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Journal of Gerontology: PSYCHOLOGICAL SCIENCES
2006, Vol. 61B, No. 1, P33–P45

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Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis

Martin Pinquart¹ and Silvia Sörensen²

¹Department of Developmental Psychology and Center for Applied Developmental Science, Friedrich Schiller University, Jena, Germany.

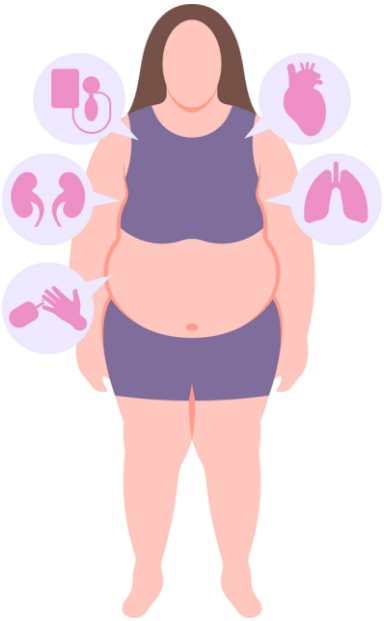
²School of Medicine and Dentistry, University of Rochester, New York.

This meta-analysis integrates results from 229 studies on gender differences in caregiver psychological and physical health, caregiving stressors, and social resources. Contrary to common perceptions, gender differences in caregiving variables were small to very small. Women had higher levels of burden and depression, and lower levels of subjective well-being and physical health. They reported that their care recipient had more behavioral problems; they provided more caregiving hours, helped with more caregiving tasks, and assisted with more personal care. Women and men did not differ in the use of informal and formal support. Statistically controlling for gender differences in stressors and resources reduced the size of gender differences in depression and physical health to levels that have been observed in noncaregiving samples. The results support stress-and-coping theories on gender differences in caregiving.

Ref: Martin Pinquart, Silvia Sörensen, Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis, The Journals of Gerontology: Series B, Volume 61, Issue 1, January 2006, Pages P33–P45, <https://sci-hub.se/https://pubmed.ncbi.nlm.nih.gov/16399940/>

KEY FINDINGS & DISCUSSION

Among  intensity caregiver, **Low**



3 times more likely

With long-term conditions

to have had their **health impacted.**



JOURNAL OF PATIENT EXPERIENCE

Figure 1 (adapted from reference 7): The Trifecta of Caregivers Self-Care

Who is taking care of the caregiver?

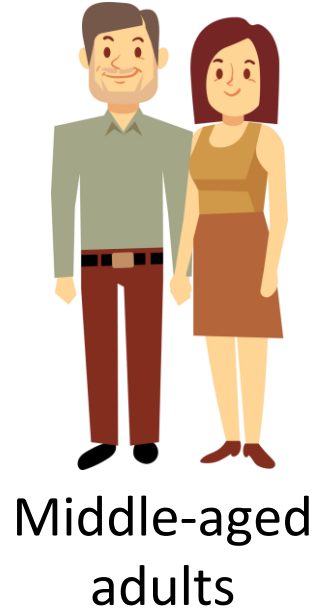
Amy Burlison Sullivan, PsyD^a, Deborah Miller, PhD^a

Ref: Sullivan AB, Miller D. Who is Taking Care of the Caregiver? Journal of Patient Experience. 2015;2(1):7-12. doi:10.1177/237437431500200103



KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
High



5 times **less** likely

to have had their **health impacted.**



KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
High



Received training

5 times more likely

to have had their **health impacted.**



KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
High



3 times more likely

Without
assistance

to have had their **health impacted.**



KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
High



3 times more likely

Without assistance

to have had their **health impacted.**



3 times more likely

Without assistance

to have had their **daily activities impacted.**



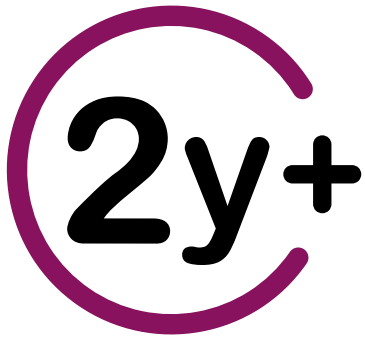
KEY FINDINGS & DISCUSSION

Among  intensity caregiver,
High



Received training

5 times more likely



Provided care for 2+ years

4 times more likely



©torwai via Canva.com

to have had their **social activities impacted.**

SUMMARY OF KEY FINDINGS

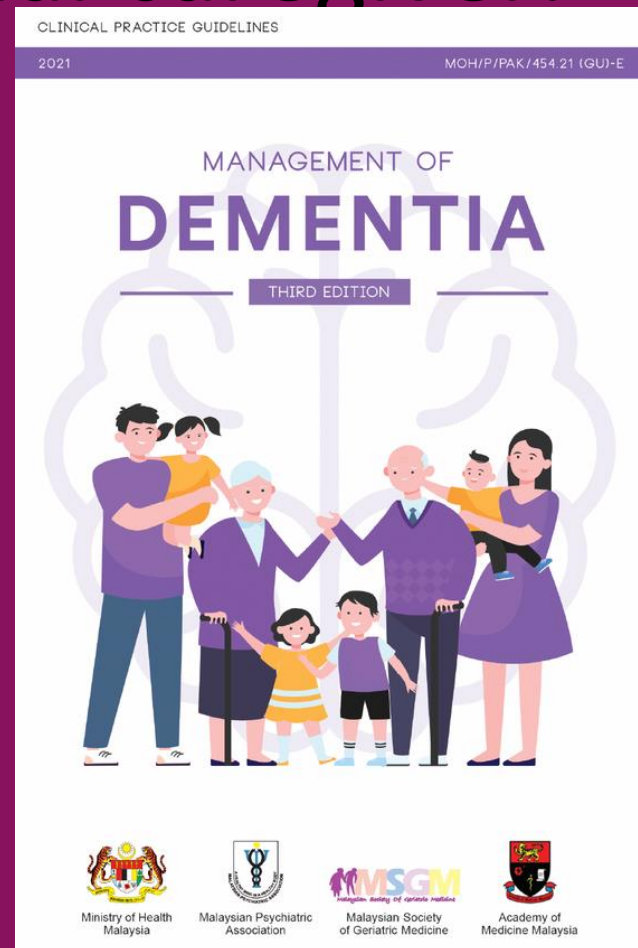
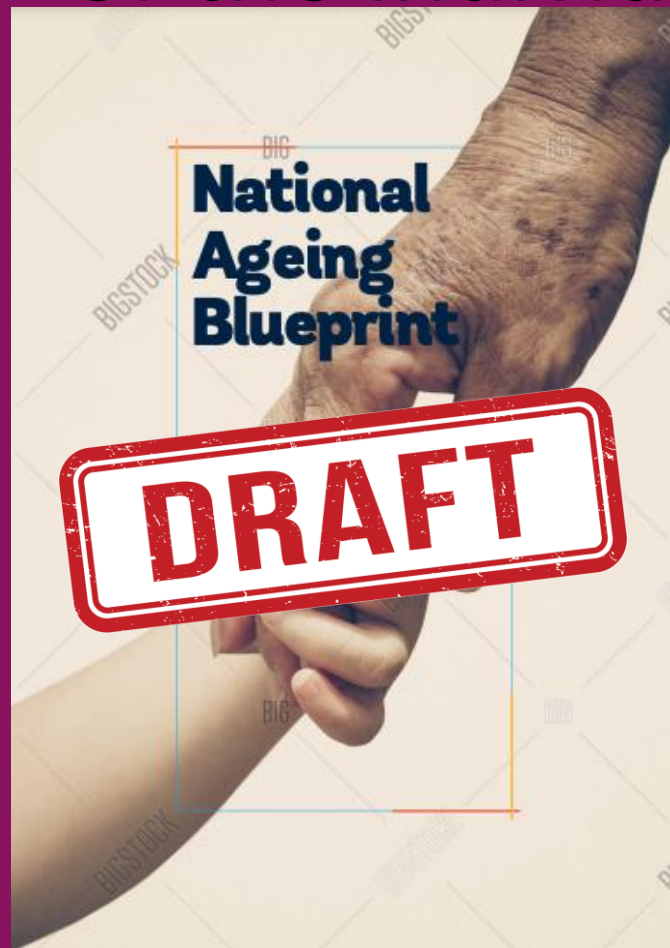
- Three-quarters of informal care recipients are older adults, and **two-thirds of older care recipients received informal care from the older caregivers.**
- **Caregiving**, regardless of intensity, has a **significant impact on caregivers.**
- **For low-intensity** caregiving,
 - **female, middle-aged adults, and those with long-term conditions** were more likely to have **negative effects on health.**
- **For high-intensity** caregiving,
 - **caregivers aged 60 and over, those who received training, and without assistance** were more likely to have **negative effects on health.**
 - **daily activities of those without assistance** were more likely to be **affected.**
 - **social activities of those who received training, and providing care for 2 years or more** were more likely to be **affected.**

RECOMMENDATIONS ON POLICY
AND PRACTICE



RECOMMENDATION #1

As caregivers have vastly different training needs, interventions must be **tailored according to the specific needs** of the individual caregiver.



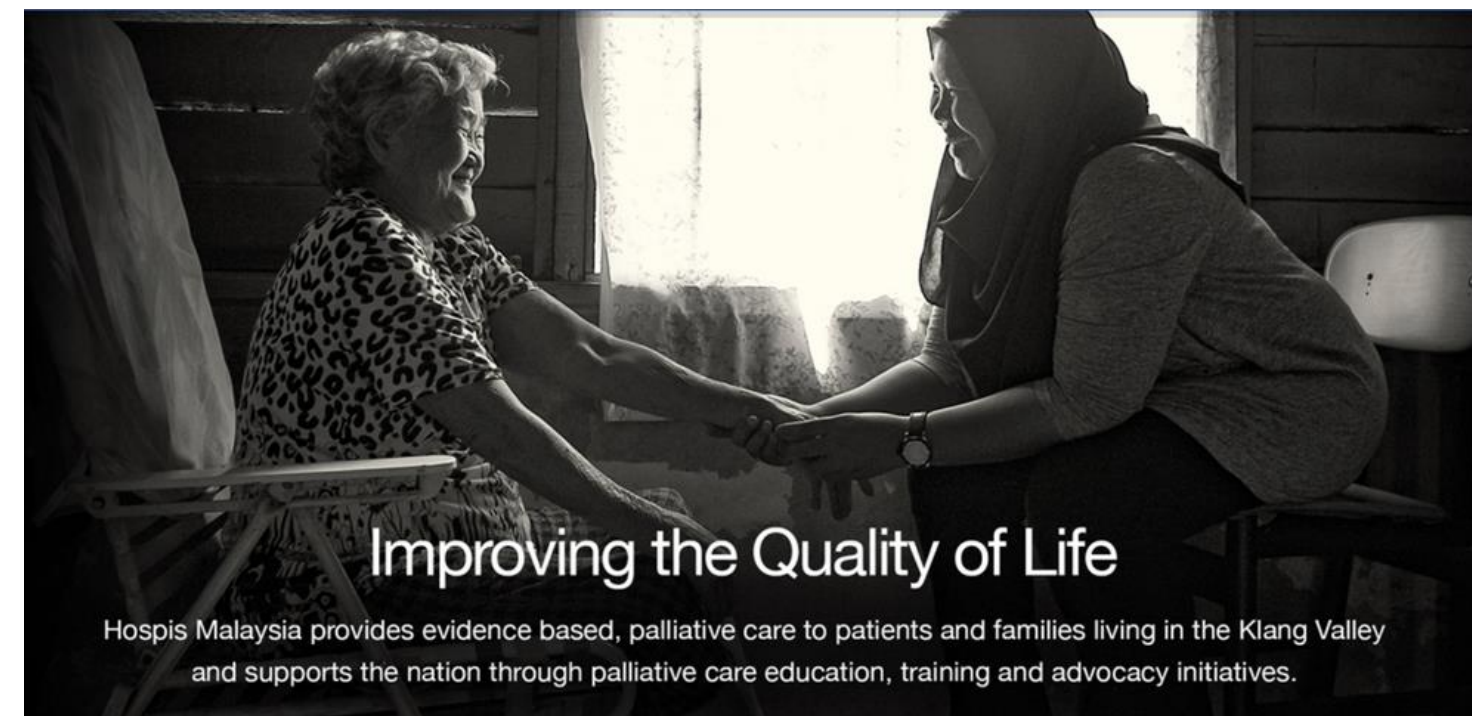
Ref: https://hq.moh.gov.my/bpkk/images/Kesihatan_Orang_Kurang_Upaya/PDF/Garis_Panduan/12_Clinical_Practical_Guidelines_-_Management_of_Dementia_3rd_ed_2021.pdf



iSupport Virtual Course
Skills and knowledge training for carers of people with dementia



Phase 1 development



Ref: <https://hospismalaysia.org/>

RECOMMENDATION #2

A strong informal care support system is necessary to provide leverage to the caregivers' tasks and responsibilities



Respite Care: Provide an alternative service to the caregivers or guardians who could place the older persons temporarily in an institution for a specific period, due to various reasons that require a temporary arrangement. Institutions provide facilities and basic services such as food, health and shelter for the older persons.

Table 8 . Cash Assistance Relevant to Caregivers and Care Recipient

Types of JKM Cash Assistance	Value
Public assistance for the needy	RM350 per month per family RM100 per month per person
Children in foster care	RM250 per month per child
Elderly persons in the hardcore poor category	RM500 per month per person
Financial assistance for PWDs not capable of working	RM300 per month per person
Financial assistance for carers of bed-ridden PWDs and the chronically ill	RM500 per month per person
Financial assistance for the needy	RM200 per month per child less than 6 years old; RM150 per month per child between 7 –and 18 years old; maximum of RM1,000 per month per family

33

Source: Department of Social Welfare, Ministry of Women, Family and Social Development Malaysia.

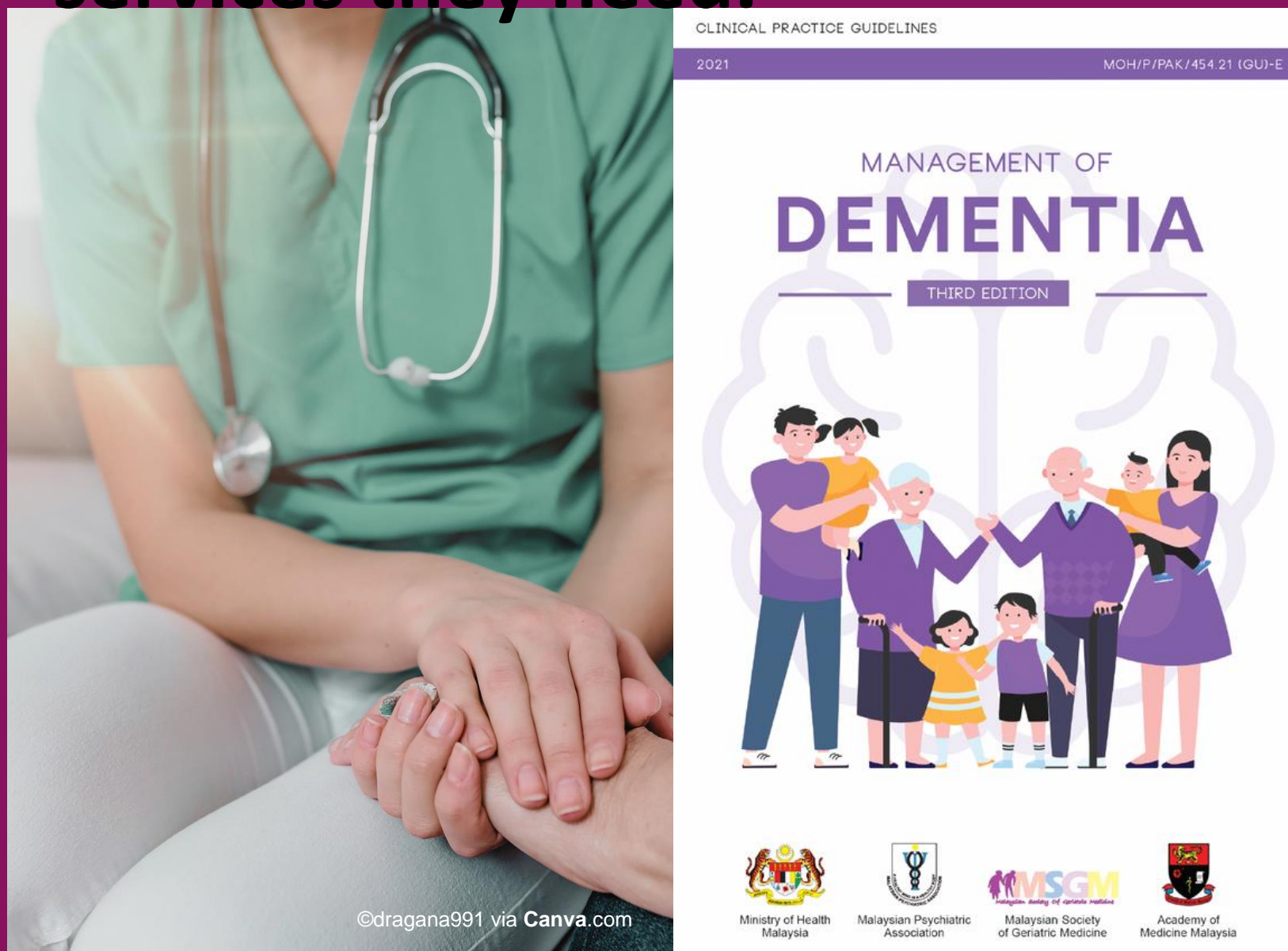
Table 9 . Income Tax Deductions Relevant to Caregivers

Types of Income Tax Relief/Allowance	Value
Basic supporting equipment for disabled self, spouse, child or parent	RM6,000 per year
Disabled spouse	RM6,000 per year
Disabled child	RM6,000 per year
PWDs (self)	RM6,000 per year
Additional exemption for disabled unmarried child older than 18 years old pursuing higher education in Malaysia or abroad	RM8,000 per year
Medical expenses for serious diseases for self, spouse or child; and Complete medical examination for self, spouse, child (limited to RM500)	Maximum RM6,000 per year
Medical expenses for parents	Maximum RM5,000 per year
Care for parents	RM1,500 per year for each parent
Insurance premium for education or medical benefit	Maximum RM3,000 per year
Childcare fees to a childcare centre or a kindergarten	RM2,000 per year
Each unmarried child and under the age of 18 years old	RM2,000 per year per child
Child relief or each unmarried child of 18 years and above who is receiving full-time education	RM2,000 per child
Deferred annuity and Private Retirement Scheme (PRS)	RM3,000 per year
Life Insurance premium	Maximum RM3,000 per year
Medical or education insurance premium	Maximum RM3,000 per year

Source: Inland Revenue Board, Malaysia

RECOMMENDATION #3

Healthcare professionals play a pivotal role in **connecting informal caregivers to the services they need.**



Session 2 Practical Caregiving Strategies

FREE

Essential Care: Practical Tips for Alzheimer's Caregivers

During the webinar:

- ✓ **Daily Care Tips:** Guidance on com
- ✓ **Handling Challenges:** Tactics for managin
- ✓ **Caregiver Resources:** Guidance on where local services and

Sign Up Now

Time: 26/10/2024

Zoom

Alzheimer's Disease Foundation Malaysia

JOBADA

ERU BEMBEKIA SUCESST

SABAH Alzheimer's Disease Foundation Malaysia

CAREGIVER SUPPORT SHARING SESSION (IN ENGLISH)

Date: 13 April 2024 (Saturday)
Time: 8.00pm – 9.30pm

An Interactive Sharing & Discussion Session
Caring for Person with Dementia/Alzheimer's

Chair By:
Dr Andy Quah Jing Yao
Geriatrician & Physician (Hospital Sungai Buloh), ADFM DCS Trainer

Note: The Caregivers Sharing Session is **STRICTLY** for caregivers, their family members & domestic care workers caring for dementia persons. To attend, WhatsApp 016 608 2513 (Jenny Ho) for Zoom Link, ID and Passcode with:

- (1) Full Name of Caregiver/family members/domestic care workers
- (2) Whom you are caring
- (3) His/her full name and age

CAREGIVER SUPPORT SHARING SESSIONS are a place to learn more about caregiving, get & give emotional support, share experiences and help reduce stress and isolation.

Caregiver Support

- Caregivers should be actively involved and supported in the management of dementia.
 - This includes assessment of the burden of caregivers.

RECOMMENDATION #4

Workplace support and flexible employment policies for informal caregivers is crucial to reduce the negative consequences of informal

PELEPASAN WAKTU BEKERJA BAGI PEGAWAI PERKHIDMATAN AWAM YANG MEMPUNYAI ANAK-ANAK KURANG UPAYA

TUJUAN

1. Ceraian ini bertujuan menetapkan pelaksanaan pelepasan waktu bekerja bagi Pegawai Perkhidmatan Awam yang mempunyai anak-anak kurang upaya.

LATAR BELAKANG

2. Selaras dengan keputusan Kerajaan mengenai perkara tersebut, Pegawai Perkhidmatan Awam yang mempunyai anak-anak kurang upaya dibenarkan menggunakan waktu bekerja biasa sebagaimana yang diamalkan sekarang untuk menguruskan kebajikan dan keperluan anak-anak mereka.

Ref: <https://docs.jpa.gov.my/docs/myppsm/PPSM/SR/Waktu-bekerja/>



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KERAJAAN MALAYSIA

PEKELILING PERKHIDMATAN SUMBER MANUSIA

WAKTU BEKERJA

VERSI 1.0 (2022)

JABATAN PERKHIDMATAN AWAM
MALAYSIA



Caregiving is a **SHARING RESPONSIBILITY** —when we balance the burdens with support, we create a healthier future for both caregivers and those they care for.

THANK
for your
YOU
attention

Suhana Jawahir
Centre for Health Equity Research (CHER),
Institute for Health Systems Research (IHSR),
National Institutes of Health (NIH)

The **IMPACT** of caregiving intensity on informal caregivers in Malaysia: findings from a national survey

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RESEARCH ARTICLE

Open Access

The impacts of caregiving intensity on informal caregivers in Malaysia: findings from a national survey



Suhana Jawahir^{*}, Ee Hong Tan, Yeung R'ong Tan, Sarah Nurain Mohd Noh and Iqbal Ab Rahim

Abstract

Background: Provision of informal care may adversely affect health, daily and social activities of the informal caregivers, but few studies have examined these effects in relation to caregiving intensity. This study examined the predictive factors associated with the effects of caregiving roles on health, daily and social activities of informal caregivers, accounting for caregiving intensity.

Methods: Data of adults aged 18 years and over from the National Health and Morbidity Survey 2019 were used. Respondent's demographic, socioeconomic, health, and caregiving-related characteristics were described using complex samples analysis. Logistic regression analysis was performed to examine the factors affecting health, daily and social activities of caregivers, accounting for caregiving intensity.

Results: Five point one percent of adults in Malaysia provided informal care. High intensity caregivers were more likely to be actively employed and provided longer duration of care compared with low intensity caregivers. For low intensity caregiving, females, those aged 35–59 years, and those with long-term condition were more likely to have negative effects on health. Daily activities of non-Malays were more likely to be affected, while no factor was found significantly associated with effect on social activities. For high intensity caregiving, caregivers aged 60 and over, those received training and those without assistance were more likely to have negative effects on health. Daily activities of those without assistance were more likely to be affected. Social activities of non-Malays, those received training and those providing care for 2 years or more were more likely to be affected.

Conclusions: Our study indicates that both low- and high-intensity caregivers have common features, with the exception of employment status and care duration. Caregiving, regardless of intensity, has a significant impact on caregivers. In order to reduce the negative consequences of caregiving responsibilities, all caregivers need assistance from the community and government, that is customised to their needs. By addressing the factors contributing to the negative effects of caregiving, a continuation of informal caregiving can be sustained through policies supporting the growing demand for informal care necessitated by an ageing population and higher life expectancy in Malaysia.

Keywords: Caregivers, Informal care, Health status, Malaysia, Population health, Health surveys

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