

Shifting the Patient Paradigm: Involving Family Caregivers for Healthy Societies

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“Ageing in Place”

“Older adults remaining in their homes and communities as they age, rather than relocating or moving into an institutional setting”



Frailty & Dementia

Frailty % (SG Senior Population)



30% Pre-Frail



5% Frail

(MOH, 2023)

*“Expected to grow exponentially,
from **5-6% currently to 27% in 2030**”
(The Straits Times, 2024)*

Dementia % (SG Senior Population)



1 in 10 seniors (> 60 years) have
dementia

*“Number of persons with
dementia...is expected to **increase to
152,000 by 2030**”
(MOH, 2023)*

Caregivers

Self-Identify as Caregivers (SG Senior Population)

70% of caregivers are aged 40 years old and above. (CNA, 2019)

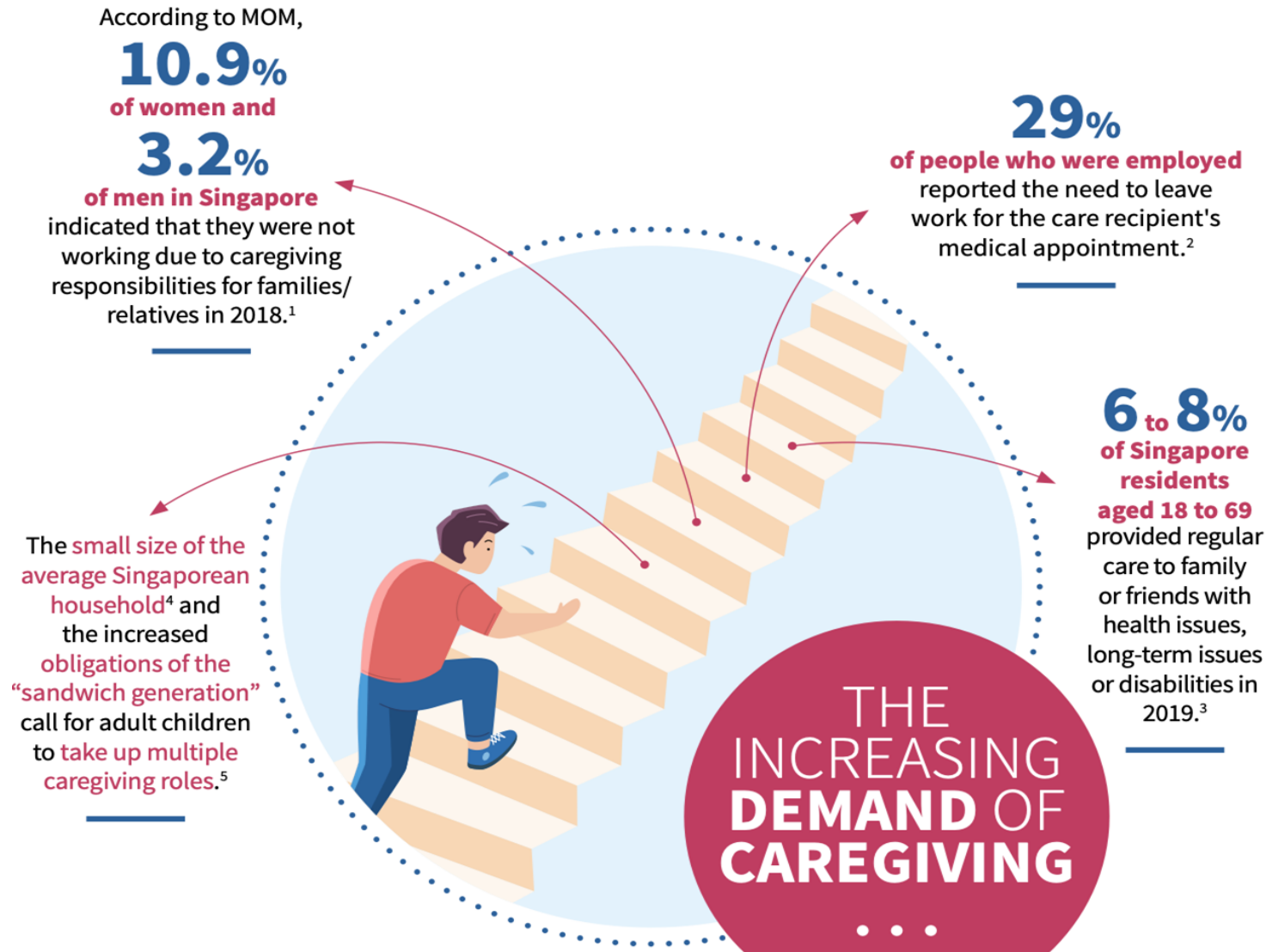


“Caregivers deal with the *physical, financial and psycho-social* responsibilities of caring for the elderly and the young” (MSF, 2021)

“There is an estimated *more than 210,000 full-time caregivers* in Singapore...”

(Today, 2023)

“Ageing in Place” – Impact on Caregivers



The demand of caregiving is likely to grow in the near future as Singapore’s population continues to age rapidly

In **2030**, **1 in 4** Singaporeans will be aged 65 and above.

Family size shrinking - old-age support ratio decrease from **4.8 today** to **2.7**

“Care for the Caregivers” – Why is it important?

Based on:



Stakeholder engagement with more than 30 caregivers since 2022

In-depth interviews with 43 family caregivers of older persons

Literature Review

Survey conducted on over 200 family caregivers community-dwelling older adults at Memory Clinic from 2018 - 2019

Baseline study of 72 caregivers looking after patients 65 years old and above in 2022

Survey conducted on 274 family caregivers of dependent persons hospitalized from 2015-2017

Common pain points:

Challenges in Direct Care

High Cost of Caregiving

Poor Caregiver Well-Being

Navigating Online Resources

Accessing Community Resources



“Care for the Caregivers” – In their words

“I have done all sorts of things, suffered..., I feel so numb” (P2) (Chew et al 2022)

*“I don’t even have any **time for myself**” (P16) (Ong et al 2021)*

*“I am very tired. I am (so) tired that **I (can) drop dead** ” (P11) (Chew et al 2022)*

*“There’s a **mental torture** in me I think like during **wartime**.” (P9) (Chan et al 2019)*

*“(Other family members) **don’t want to learn** (how to help)” (P4) (Ong et al 2021)*

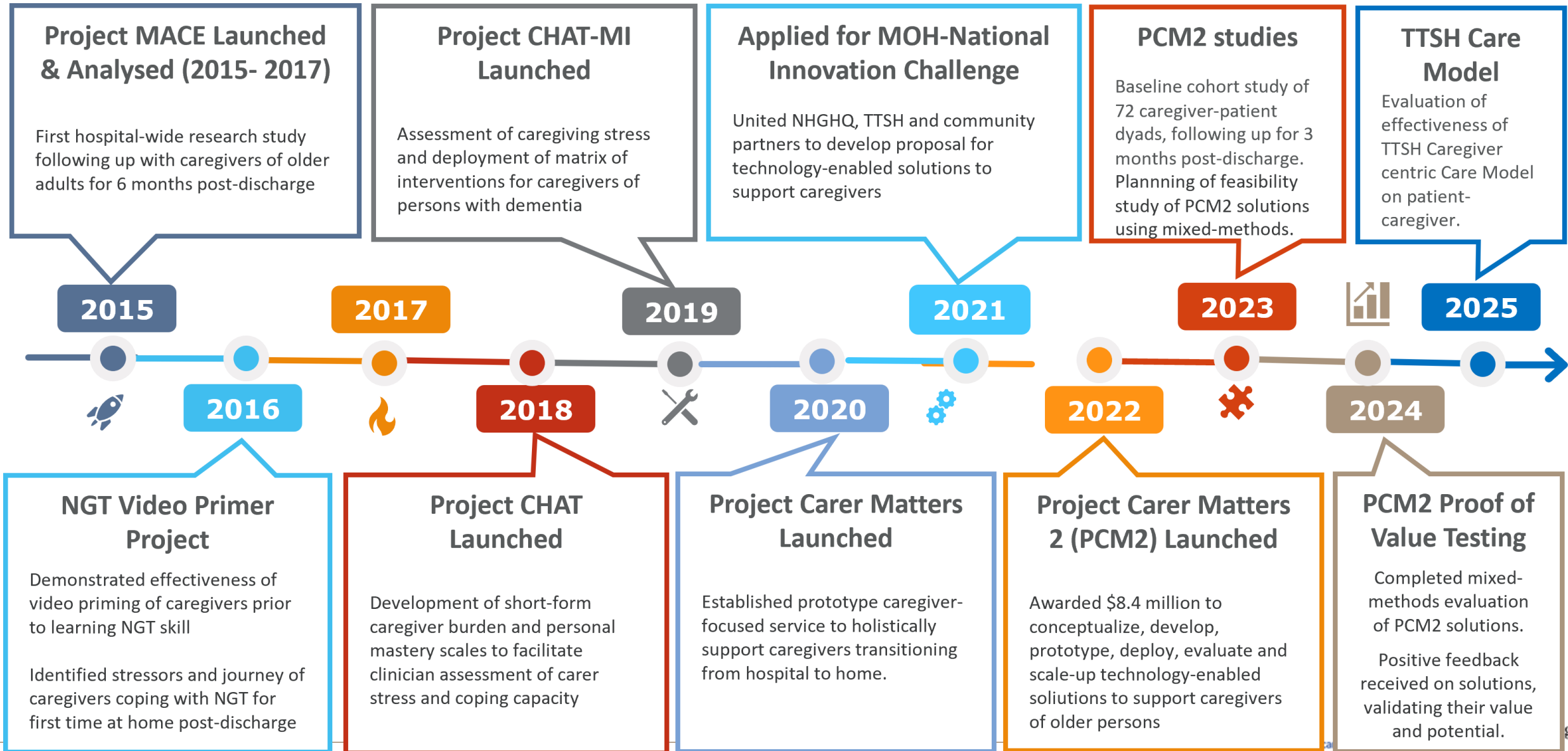
Chan EY, et al. Crossing, Trudging and Settling: A phenomenological inquiry into lived experience of Asian family caregivers of older persons with dementia. *Geriatr Nurs*. 2019 Sep-Oct;40(5):502-509.

Chew EYH, et al. '24/7' Caregiving: A Qualitative Analysis of an Emerging Phenomenon of Interest in Caregiving. *Int J Environ Res Public Health*. 2022 Dec 19;19(24):17046.

Ong ZL, et al. Four of a kind: Salient caregiver archetypes to better understand the psychosocial needs and behavioral patterns of dementia caregivers in Singapore. *Geriatr Nurs*. 2022 Jan-Feb;43:299-308.



“By, With and Through” engagement of research with caregivers



Project MACE (2015-2017)- Caregivers at risk

Followed up 274 caregivers of older persons for 6 months post-discharge



1 in 3 caregivers of older patients in our hospital screened positive for risk of depression, high anxiety and poor quality of life

Unmet psychosocial needs and don't know where to find help.

Increased risk of hospitalization and institutionalization of care recipient

Chan EY, et al. Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. J Nutr Health Aging. 2018;22(10):1238-1245.

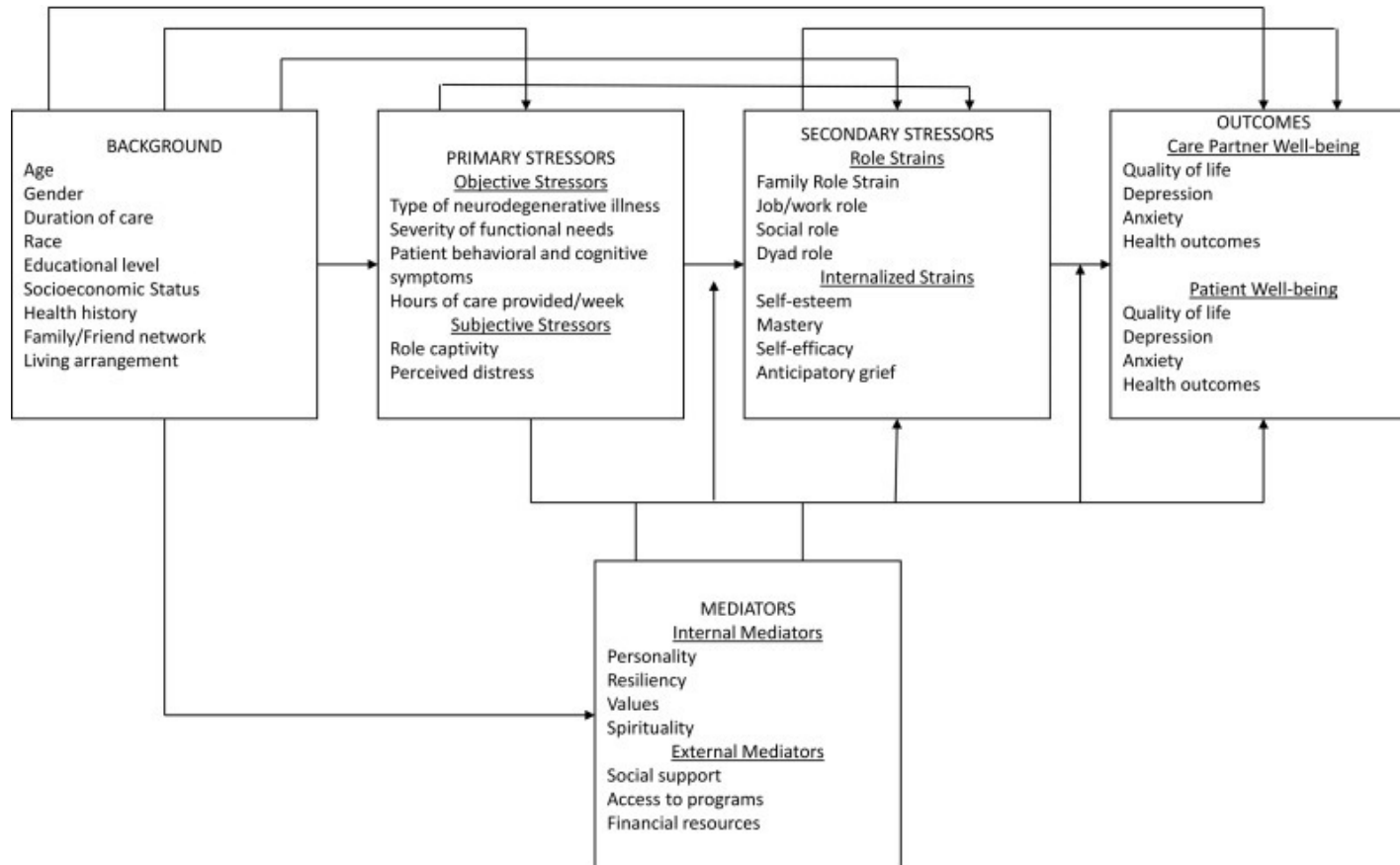
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Ong ZL, et al. Four of a kind: Salient caregiver archetypes to better understand the psychosocial needs and behavioral patterns of dementia caregivers in Singapore. Geriatr Nurs. 2022 Jan-Feb;43:299-308.



Project MACE (2015-2017) – Mastery



High mastery: Increased sense of control over person's life

Mastery found to have a protective effect against depressive symptoms in caregivers ($\beta = -0.51$, $F = 17,65$, $p < 0.001$)

Potentially modifiable, raising mastery can improve caregivers' capacity to cope

Chan EY, et al. Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. *J Nutr Health Aging*. 2018;22(10):1238-1245.

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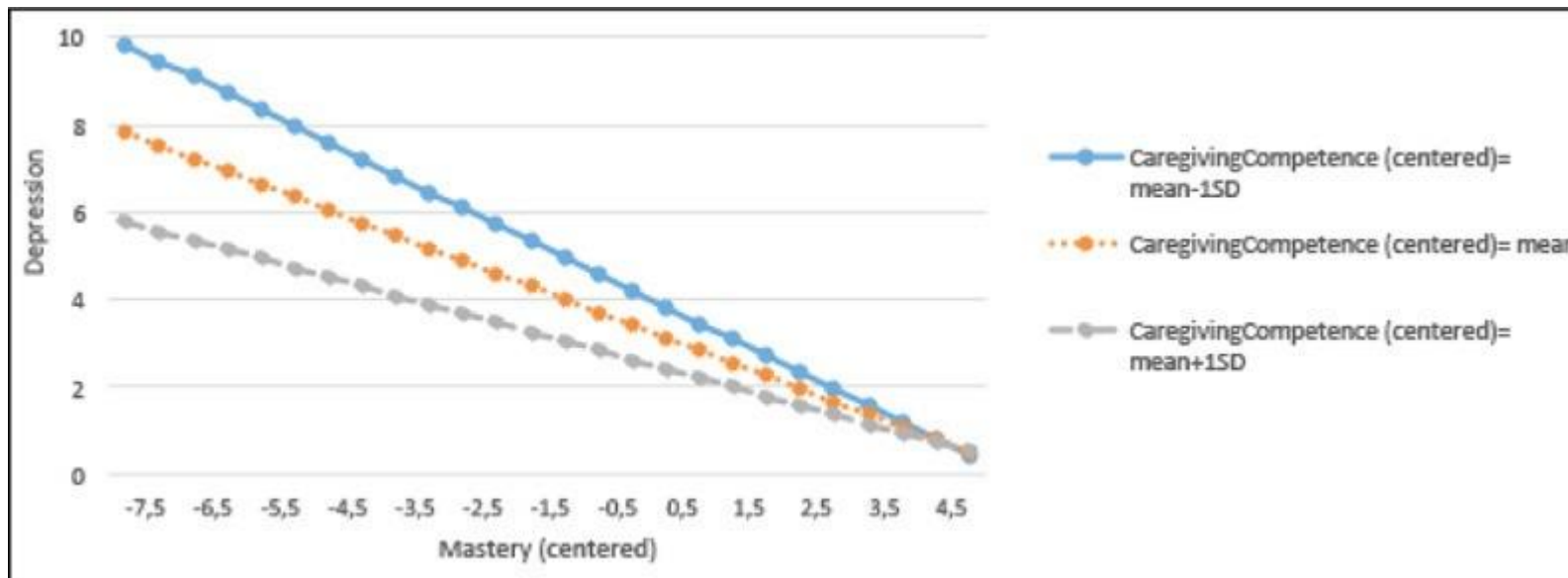
Pearlin LI, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990 Oct;30(5):583-94.



Project MACE (2015-2017) – Mastery

Caregivers with higher mastery reported lower levels of depression

Association stronger among caregivers with lower levels of perceived competence in their caregiving
=> Having an overall sense of control over their lives could help overcome sense of inadequacy in caregiving “Things are not perfect but I can handle this”



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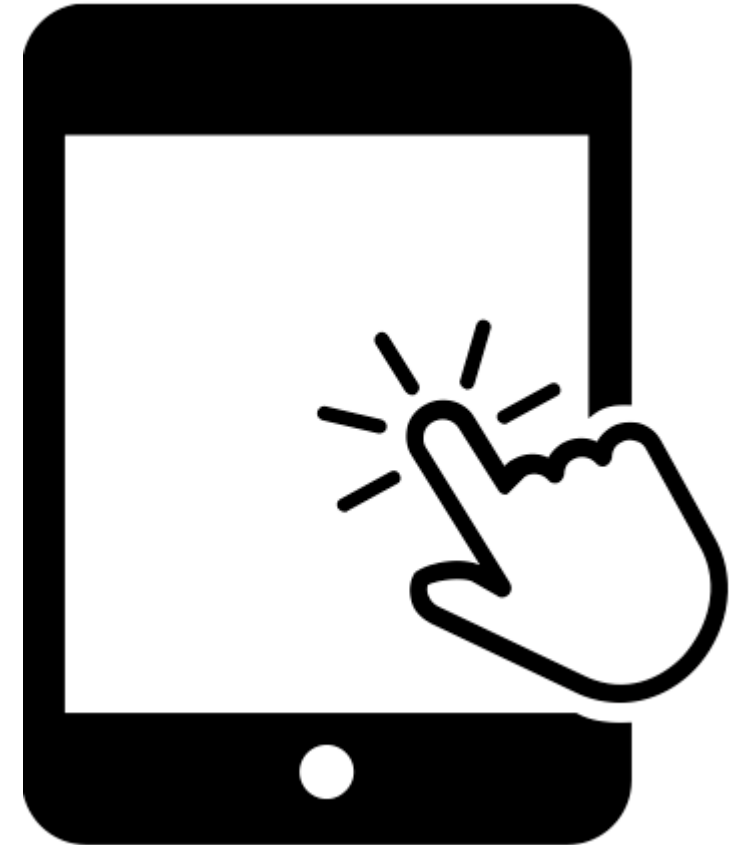


Nasogastric Tube Video Primer Study (2016)

Examined effect of video-enhanced training for caregivers learning nasogastric tube feeding in hospital

Video-enhanced training increased median number of correct steps during first attempt by 40% from 5.0 (IQR: 3.5-6.0) to 7.0 (IQR 3.5 – 7.5)

75% of caregivers receiving video-enhanced training completed training in 6 sessions, compared to 9.3 if they received standard training => Potential to save 1 day of hospital stay



Kwok MWS, et al. I see, I learn, I do: Development and evaluation of a video-enhanced nasogastric tube feeding training programme for caregivers. Nurs Open. 2023 Apr;10(4):2357-2365.

Loke SXY, et al. Transiting Back Home: Caregivers' Lived Experiences in Caring for Loved Ones on the Nasogastric Tube in the Home-Setting in Singapore. J Transcult Nurs. 2023 Sep;34(5):343-355.



Project CHAT-MI (2018-2019)

Hybrid Burden-Mastery Tool

Mastery-5

How strongly do you agree or disagree with these statements about yourself?

There is really no way I can solve some of the problems I have.

I have little control over the things that happen to me.

I often feel helpless in dealing with life's problems.

Sometimes I feel that I am being pushed around in life.

There is little I can do to change many of the important things in my life.

ZBI Burden

After I became a caregiver...

I feel I don't have enough time for myself.

I feel stressed between caring for my care recipient and trying to meet other responsibilities for my family or work.

I feel that my social life has suffered because I am caring for my care recipient.

I feel I will be unable to take care of my care recipient much longer.

I feel I have lost control of my life.

I feel strained when I am around my care recipient.

I feel that my health has suffered because of my involvement with my care recipient.

I feel I should be doing more for my care recipient.

I feel I could do a better job in caring for my care recipient.

Lim ZX, et al. Psychometrics of the Pearlin Mastery Scale among Family Caregivers of Older Adults Who Require Assistance in Activities of Daily Living. Int J Environ Res Public Health. 2022 Apr 12;19(8):4639.

Lim ZX et al. Development and Validation of a Multidimensional Short Version Zarit Burden Interview (ZBI-9) for Caregivers of Persons With Cognitive Impairment. Alzheimer Dis Assoc Disord. 2023 Jan-Mar 01;37(1):59-65.

Chan EY, et al. Exploring the Feasibility of a Caregiver Burden-Mastery Hybrid Assessment Tool With Decision Matrix in a Memory Clinic: A Multimethod Study. SAGE Open Nurs. 2024 Dec 19;10:23779608241307002.

Established short-form caregiver burden and mastery assessment tool, pair it with matrix of interventions to guide clinicians

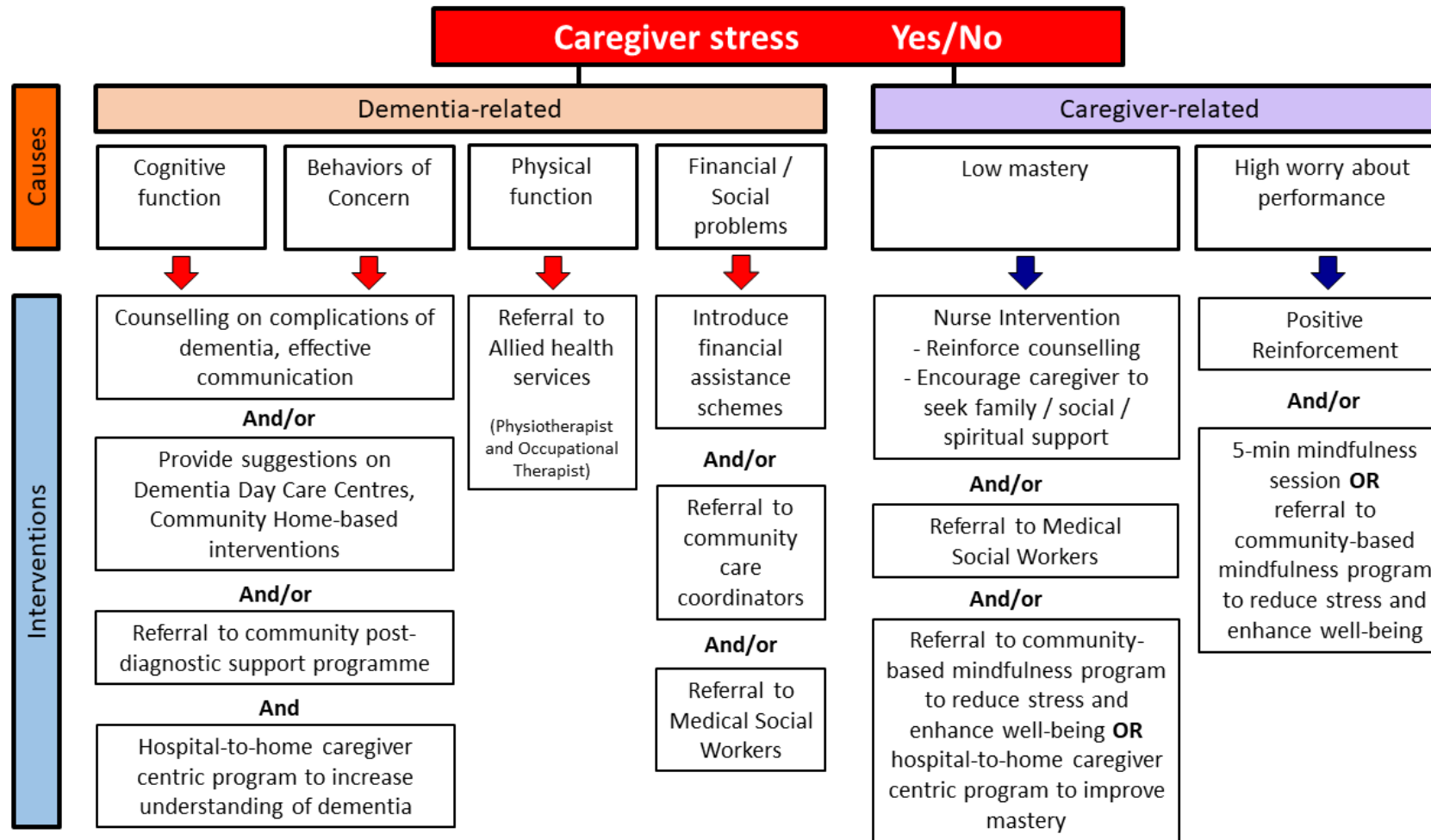
Tested in outpatient memory clinic setting in Singapore for caregivers of persons newly diagnosed with dementia

88% of caregivers found screening tool easy to understand

Matrix tool found to be acceptable, feasible and useful



Project CHAT-MI (2018-2019) - Matrix



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Lim ZX et al. Development and Validation of a Multidimensional Short Version Zarit Burden Interview (ZBI-9) for Caregivers of Persons With Cognitive Impairment. *Alzheimer Dis Assoc Disord*. 2023 Jan-Mar 01;37(1):59-65.

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Project CHAT-MI (2018-2019) - Results

Opportunity to check-in on wellbeing

“(The) questionnaires helped me to reflect and introspect on areas where I need more support, and (think about) whether I’ve overlooked my own wellbeing”

- CG5, regarding screening questions

Guided clinicians in probing of caregiver issues

“(CHAT-MI) guides clinician to dig more [probe] when they score high on mastery and burden... Having (CHAT-MI) will guide the consultation process, and nurses will know how to intervene [provide recommendations for caregivers]. The consultation is more structured and systematic compared to before”

- HCP1, regarding usage of matrix

Provides ancillary insights on caregivers to guide consultation

“The tool is able to pick up that she [caregiver] is stressed, and the nurse gave suggestions for (referrals to) [caregiver-centric programs] or [mindfulness programs]”

- HCP 5

“It would be good because you are able to identify high burden scores in a case [caregiver] that you don’t expect”

- HCP 6

Lim ZX, et al. Psychometrics of the Pearlin Mastery Scale among Family Caregivers of Older Adults Who Require Assistance in Activities of Daily Living. *Int J Environ Res Public Health*. 2022 Apr 12;19(8):4639.

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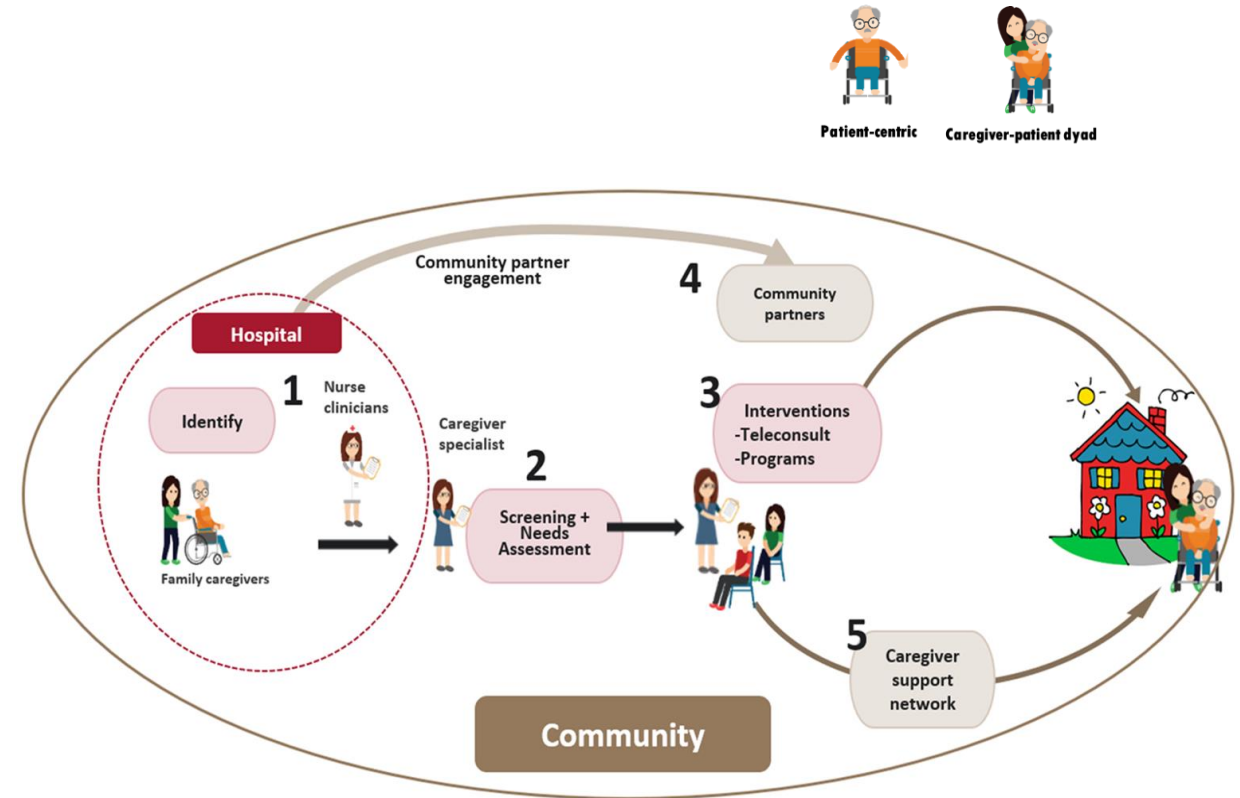


Project Carer Matters (2020-2022)

First hospital-to-home network in SG to screen, identify & provide targeted interventions for at-risk family caregivers

Introduced virtual support and engagement over COVID-19 pandemic, filling vital caregiver need over Circuit Breaker

Improved caregivers' knowledge, stress levels and confidence in care



Chan EY, Glass GF Jr. Delivering a holistic hospital-to-home framework to support family caregivers of persons with dementia: Protocol for a feasibility study. *J Adv Nurs*. 2022 May;78(5):1513-1523.
Chan EY, et al. Applying the RE-AIM framework to evaluate a holistic caregiver-centric hospital-to-home programme: a feasibility study on Carer Matters. *BMC Health Serv Res*. 2022 Jul 19;22(1):933
Wu LT, et al. Developing a theory of change to guide the design and implementation of a caregiver-centric support service. *BMC Health Serv Res*. 2024 Dec 18;24(1):1620.



Project Carer Matters (2020-2022)

Training programmes delivered

Training Courses	Courses Description
CARERS (Coaching, Advocacy, Respite, Education, Relationship, Simulation) Programme (Chiu et al, 2013)	A therapeutic group intervention that features a unique hands-on simulation exercise in the presence of a simulated patient to practice the application of problem-solving techniques. The course is co-led by two facilitators and held weekly over eight weeks in small groups of four to six participants.
TEACH Programme	An interactive group course aims to build caregiving skills and provide emotional support for family caregivers. Sessions are tailored to central themes of caregiving (changing relationship, community resource navigation, future planning, self-care).
Understanding Dementia	This course helps caregivers understand dementia, the nature of Behavioural and Psychological Symptoms of Dementia (BPSD) and general approaches to challenging behaviours.
Problem-solving techniques	This course introduces a five-step problem-solving technique adapted from the CARERS programme. This is a group session tailored to help caregivers address practical problems faced (Chiu et al., 2013).
Self-care techniques	This course will help caregivers recognise the importance of self-care and learn practical self-care tips.
Caregiving Essentials	This group course will help caregivers understand more about caregiving and provide practical caregiving tips.
Public forums/Seminars	Seminars are designed to provide generic sought-after information for caregivers, such as financial support availability and home safety.

Sample resources

Caregiving Activities

-  **Basic activities of daily living:**
Feeding, Bathing, Walking
-  **Shopping, Housekeeping, Food preparation**
-  **Ensuring physical and mental well-being**
-  **Managing medical condition(s)**
-  **Managing finances**
-  **Decision making**
-  **Advocacy needs**
-  **Coordination of care needs**






- Knowledge and Skills of Caregiving**
What caregiver knowledge and skills do I need? Where can I find them?
- Strategies to Cope with Caregiving**
How can I cope with the challenges and demanding nature of caregiving?
- Supporting Yourself**
How can I care for myself?
- System Navigation**
What are the available community resources? Where can I find them?



Project Carer Matters (2020-2022) – 2021 Pilot

Problem-solving support

“I let out whatever my problems, and (the caregiver support nurses) are able to listen and understand me, and sometimes give me some advice pertaining to that specific problem.”

- CG18, regarding programmes attended (73F, caring for spouse with dementia)

Better-prepared for future needs

“It gives me (a better understanding) on what I can prepare for, what I can expect on the caregiving journey, and what kind of help I can receive.”

- CG21, regarding programmes attended (46F, caring for mother with dementia)

Digitalization improved caregiver participation

“So it is kind of easy, it is good, this form. (Easy to) get it done.”

- CG3, regarding online needs assessment form (62M, caring for mother with health problems)

Convenient to participate online

“It is not going to be long, it is Zoom... that means I can log in at home, I do not have to spend to (travel).”

- CG21, regarding programmes attended (46F, caring for mother with dementia)

550

Caregivers assessed for needs and provided tailored resources

69

Caregivers given telesupport

252

Caregivers attended in-house programs

Comparison of dementia knowledge before and after Understanding Dementia Virtual Course

Variables	Pre-test (n = 61) Mean (SD)	Post-test (n = 57) Mean (SD)	p-value
Total Score (Range 0-8)	5.39 (1.63)	6.81 (1.32)	<0.001

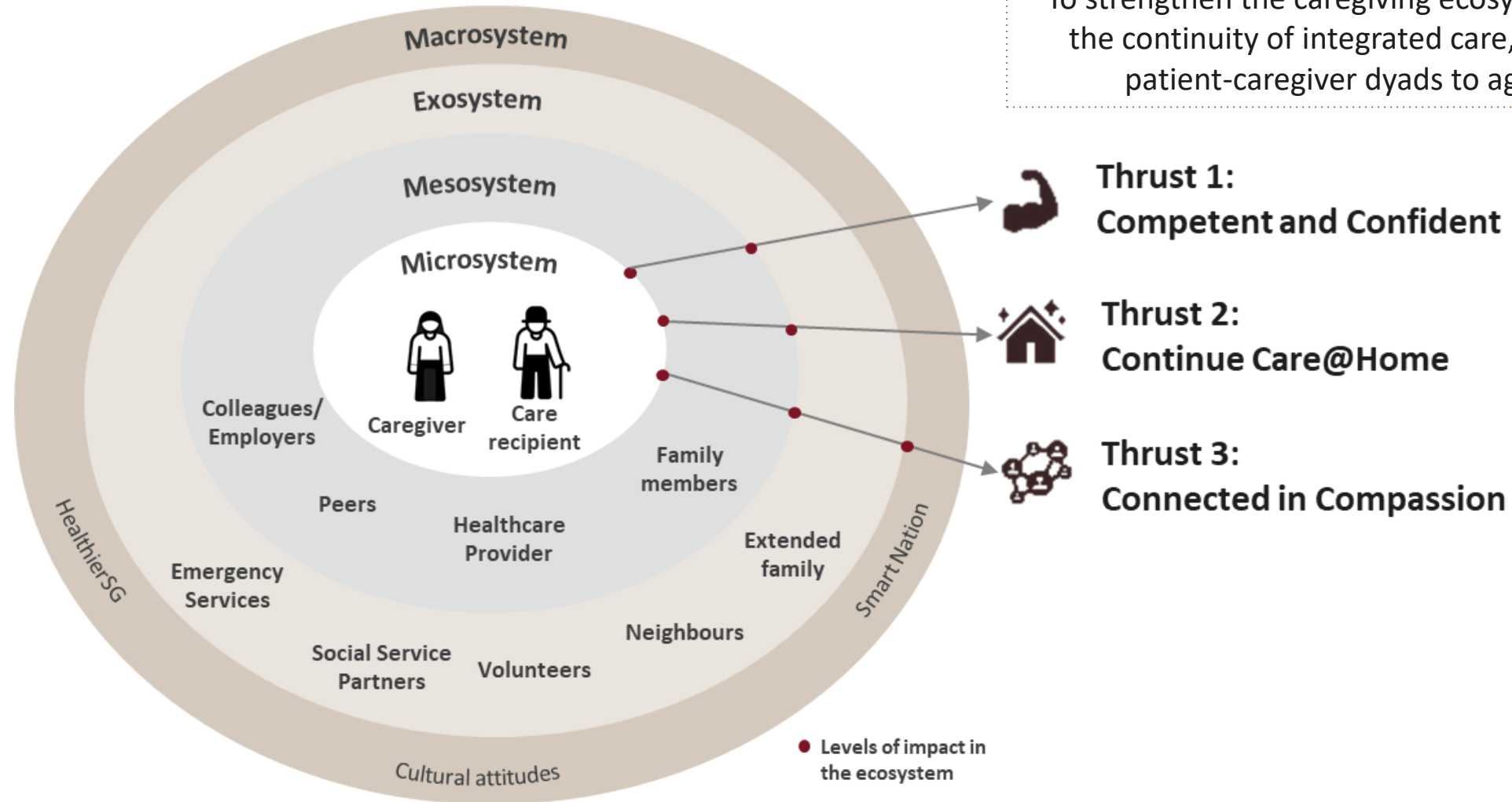
Mean Difference = 1.41 (95%CI: 0.87 – 1.96)



Project Carer Matters 2 – A seamless flow of support from hospital into society

Goal of PCM2

To strengthen the caregiving ecosystem and ensure the continuity of integrated care, which enables patient-caregiver dyads to age-in-place.





Must Have
(Information that are "critical" and may not be easily located through searching → using priority & emergency)

② Tubes and Lines (NGT and Catheters)	① Monitoring for Warning Signs
② Wound Management	Preventing Falls in the Elderly
Nutrition for My Family Member	Sleep for My Family Member
Activities of Daily Living	Medication
Pain Management	Financial Help
	Discharge Checklist

Communication, mood, & behaviour management of different symptoms

Should Have
(Information that are "localised" and may not be easily located though interest but are less critical / less urgent)

Creating a Safe Home Environment	Help with Meals
Activities to Engage My Family Member	Help with Medical Appointments
Nutrition/ Dietary Management	Impact of Caregiving on Me
Community Resources	Planning for the Next Phase
Home Monitoring	Help with Housekeeping
Respite care	Ways to get help to transport for wheel-chair / bed-bound patients

Nice to Have
(Typically information that can be easily derived from the internet)

My Physical Well-Being
My Social Well-Being
My Psychological Well-Being

① Monitoring for warning signs Reason: Important to know the critical signs which would require us to send our family members for immediate medical help.

② Tubes & Lines Reason: this not an A&E → ~~As to the~~ these caregivers will need to know how to deal to the tubing issue in order to protect patients from hunger.

③ Wound management Reason: Imp + know how to manage wound like bed sore so that the wound does not progress to an emergency.

→ when is a condition or symptom critical enough to go to A&E?

→ How to help my mum when she has certain symptoms.

→ where to look for food that is easy to be eaten by those who cannot be swallowed?

→ where to get transport for wheelchair-bound patients & cost?

— Internet —

— Ask doctor —

— friends & similar experiences —

— email doctor/hnl agencies like HCA notice, nursing foundation, —

— Internet —

google medical websites

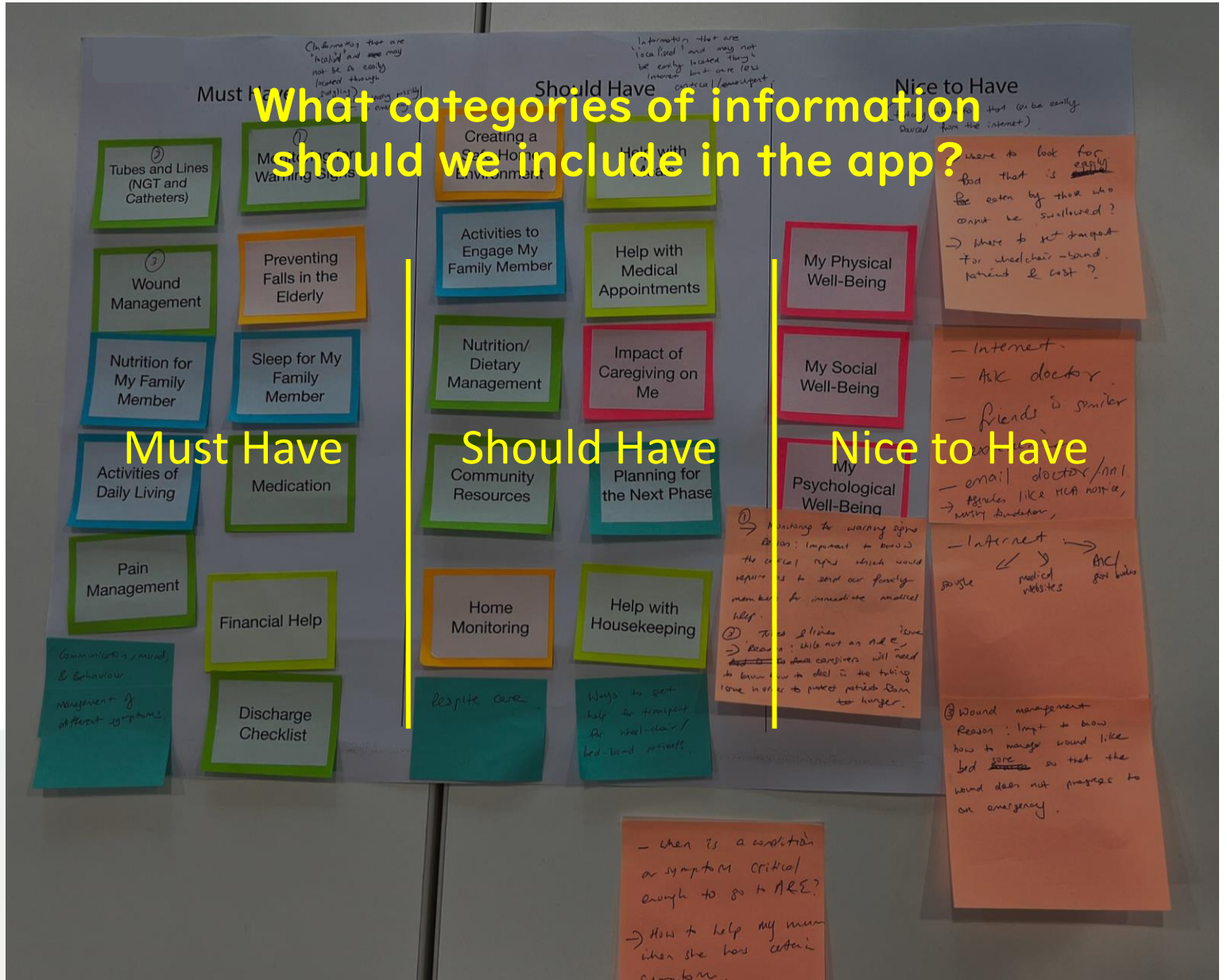
hnl got books



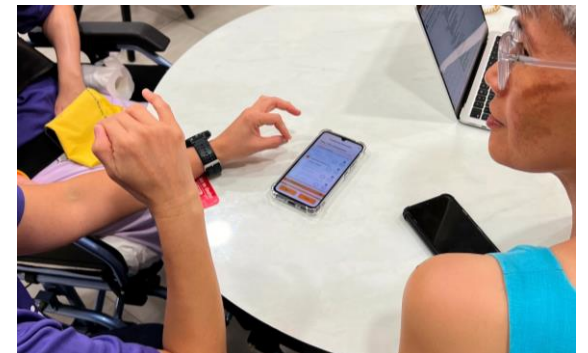
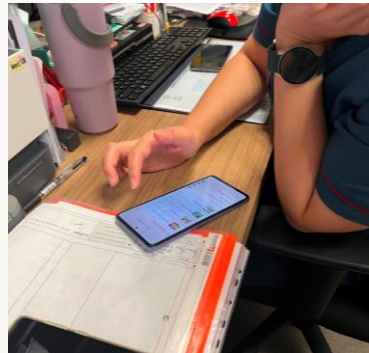
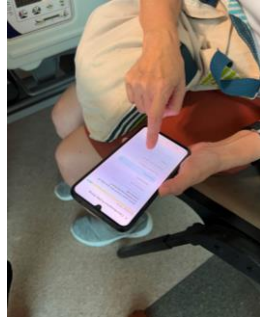
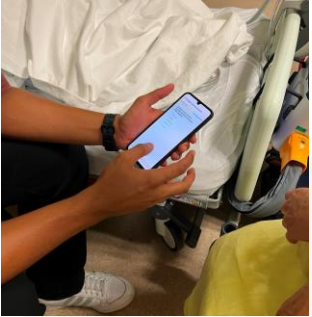
Where do you go to find answers?

What do you search for?

What challenges do you face?



Creating Prototypes through Iterative Cycles





Conclusion

- Paradigm shift needed to not just focus on the aged patients, but also that of their families, to achieve ageing in place
- Better care for caregivers contributes to better care for seniors and healthier societies

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Thank You



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