



CARExpert PROGRAMME

14 October 2020
Wednesday
9am - 10:30am SGT
Webinar via Zoom

Caring for persons with dementia and their caregivers in the community

Towards a Sustainable Community-Based
Dementia Care System



Centre for
Ageing
Research &
Education

SPEAKER



Dr. Angelique Chan

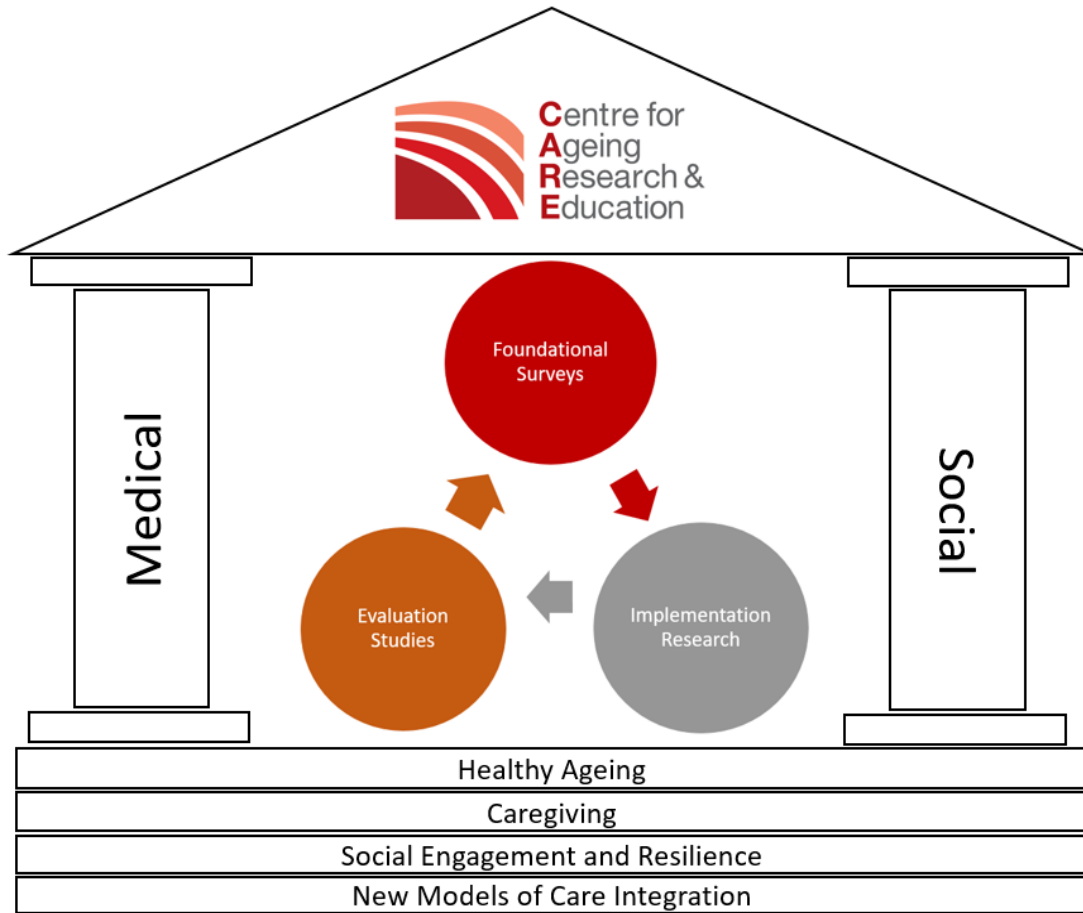
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DukeNUS
Medical School

CARE - A Translational Research Centre



Vision

To achieve health, social inclusion and a high quality of life for our ageing population

Mission

- Provide an environment that enables interdisciplinary research and education on ageing
- Implement and evaluate best practices to improve health and functions of older adults
- Inform policy and practice agenda on ageing

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- **Technical issues**

- > Please use the Chat box/option. CARE administrative staff will try and address your issues

- **Questions and Answers**

- > Your microphone and video functions have been disabled

- > The question and answer segment will be at the end of the talk

- > You have two ways of asking questions:

- Type your question(s) out in the Q&A box/option

- "Raise your hand" to ask your question(s) verbally

- > Please introduce yourself before asking your question/s

- **Evaluation survey**

- > A link will be provided at the end of the session. Your completion will be much appreciated!

Caring for Persons with Dementia: Towards a Sustainable Community- Based Dementia Care System

A/P Angelique Chan

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- Funding: National Innovation Challenge grant
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Introduction

- Singapore is ageing rapidly, by 2030 23% of the population will be aged 65+
- 10% of the older Singaporeans (60+) have dementia
- By 2030, it is projected that 90,000 Singaporeans will have dementia
- Relatively little is known about the needs of community-dwelling persons with dementia (PWDs) and their caregivers in Singapore
- Lack of research evaluating the impact of interdisciplinary and community-based dementia care systems

Research Aims

- Identify unmet needs of cognitively impaired older persons (CIP) and their caregivers
- Assess levels of:
 - cognitive impairment in the community,
 - behavioural problems of older adults with dementia,
 - caregiver burden, and
 - quality of life
- Evaluate an interdisciplinary, community-based dementia care system
- Understand implementation issues and assess cost-effectiveness of intervention
- Develop a blueprint for a dementia care system in the community

Outcome Measures

- Mini-Mental State Examination (MMSE)
 - Widely used test of cognitive function among older persons
 - Tests orientation, attention, memory, language, and visual-spatial skills
 - 30-point questionnaire (20-24 suggests mild dementia; 13-19 suggests moderate dementia; 12 or less suggests severe dementia)
- Revised Memory and Behaviour Problems Checklist (RMBPC)
 - Assesses presence of behaviour problems in dementia patients, and extent of caregiver distress associated with those problems.
 - 24-item caregiver-reported measure
 - Higher scores indicate behaviour problems are more frequent and upsetting for caregiver
- Camberwell Assessment of Need for the Elderly (CANE)
 - Assesses needs of older persons, particularly those with mental health disorders.
 - Needs assessed in 24 areas of life across health, social, and psychological domains.
 - Response categories – No need; Met need; Unmet need; Unknown

Outcome Measures (continued)

- Zarit Burden Interview (ZBI)
 - Caregiver self-reported measure identifying caregiver burden in terms of personal strain and role strain
 - Scores 0-20 suggest little to no burden; 21-40 suggest mild to moderate burden; 41-60 suggest moderate to severe burden; 61-88 suggest severe burden (Hebert et al., 2000)
- Health-related Quality of Life (EuroQol 5D)
 - Standardised non-disease specific instrument for assessing health-related quality of life
 - Self-reported description over 5 domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression)
 - Self-rated valuation using a visual analogue scale of 0-100 (0=worst imaginable health state; 100 = best imaginable health state)

Study Components

Phase I: Community Needs Assessment

- Understand the unmet needs of CIP and their caregivers in Whampoa community
- Quantitative Community Needs Assessment (eligibility criteria)
 - Singapore citizen/PR aged 60 and above
 - Screened positive for cognitive impairment ($AD8 + 2 \text{ MMSE score} \leq 8$)
 - Has a nominated primary caregiver aged 21 or older
 - Residing within Whampoa
- Qualitative interviews with CIPs, their caregivers, and community members

Phase II: Evaluation of Dementia Care System Pilot

- Survey interviews at:
 - Baseline, Follow-up after 6 months
- In-depth interviews
 - 3 months after baseline
- Cognitive Therapy Programme (ABLE)
 - Baseline, Follow-up at 3 & 6 months (7 Control; 10 Intervention)
- Cost Effectiveness analysis

Intervention: Hua Mei Dementia Care System (DCS)

DCS Model of Care

- A dementia-specific primary care and care management service modeled after the Person Centered Medical Home concept through the provision of primary care, behavioral management, psychosocial support, and social engagement
- An integrated, inter-disciplinary team comprising of a primary care physician, a social work and a nurse care manager, a dementia care program assistant (DCPA) and an assistant care manager
- Team members trained to provide person-centered care and support to the person with dementia, family members and the caregivers with the goal of empaneling the CR with the primary care physician for ongoing care, and a shorter term intervention with the care management team to build the capacity of the CR and the family for self care by arranging appropriate services and caregiver/family education and preparation
- A holistic approach to care through partnership with the family members, caregivers, service providers, and community members in managing the medical health and social support environment of the client.

DCS Team Members and Roles

Team Member	Key Roles
Medical Doctor	<ul style="list-style-type: none">• Medical assessment and treatment• Comprehensive medical care plan• Health monitoring• Medical reports and fiduciary assessment• Liaise with other primary care doctors and specialists
Staff Nurse	<ul style="list-style-type: none">• Comprehensive needs assessment• Nursing and medical care plan• Lead in planning for caregiver education and PWD therapy

DCS Team Members and Roles.....

Team Member	Key Roles
Care Manager (Social Worker)	<ul style="list-style-type: none">• Psychosocial assessment of PWD• Develop plan for caregiver support and care coordination• Coordination of referrals, enrolment, discharges, contracting with patients, home visits, counselling services, legal and financial planning
Assistant Care Manager	<ul style="list-style-type: none">• Provide support to care manager in all activities above
Dementia Care Programme Assistant (DCPA)	<ul style="list-style-type: none">• Develop activities to engage PWD• Provide caregiver education, assistance with ADLs• Monitor health, caregiver dynamics and stress• Consult and coordinate with staff nurse and care manager in caring for clients and family• Log diary observations for DCS team

Intervention Process

Referral & Screening

Admission based on eligibility criteria

- Diagnosis of dementia
- Aged 60+
- In need of care management (such as challenging behaviour, caregiver stress, complex health needs)
- Lives within service boundary

Needs Assessment at home

Assessment by multidisciplinary DCS team

- Medical review to confirm and stage dementia
- Comprehensive assessment (Functional, medical, behavioural, psychosocial)
- Care planning
- Assessment of caregiver/family needs and issues

Intervention

Implementation of care plan

- Review & align care plan with family
- Coordinate required services
- Home visits for acute & ongoing health and psychosocial needs
- Weekly team reviews
- Telephone consultations

Follow Up

Review of care plan after 3 and 6 months

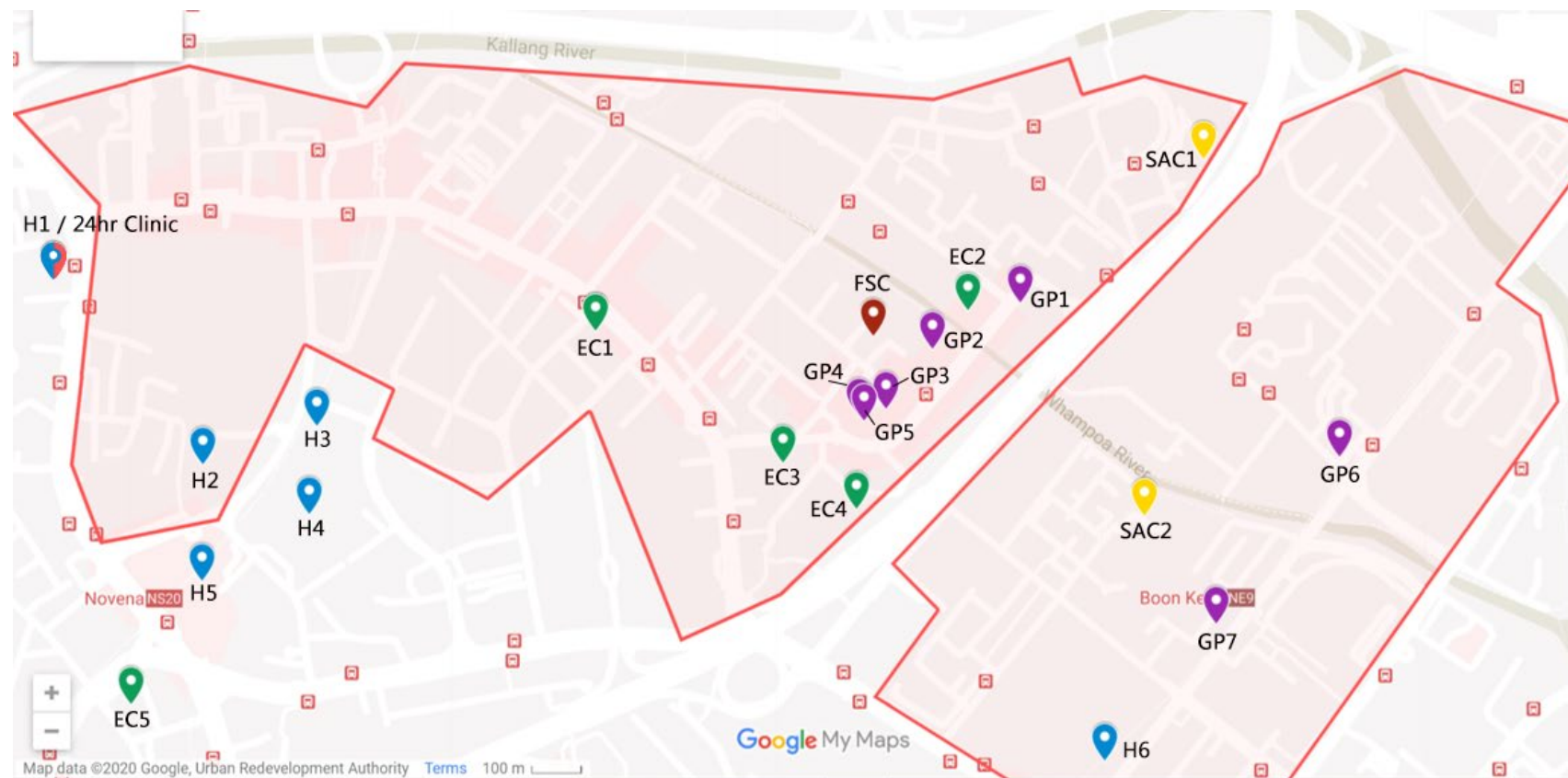
- Review and revise care plan to resolve issues
- Plan discharge with most appropriate community long-term care support system for CR (e.g. day center plus primary care practice) and care giver/family

Transition / Discharge

Discharged from DCS

- When assessed to be stable and care giver/family able to manage care independently, or
- Care recipient moves out of catchment area
- Death of care recipient

Landscape of Services in Whampoa



GP

- GP1 - President Medical Clinic
- GP2 - Winsome Medical & Dental Centre
- GP3 - Access Medical (Whampoa)
- GP4 - Whampoa Clinic
- GP5 - Wee's Family Clinic & Surgery
- GP6 - My Family Clinic (St George)
- GP7 - 18 Clinic



Hospital

- H1 - Thomson Medical Centre
- H2 - Mount Elizabeth Novena Hospital
- H3 - Ren Ci Community Hospital and Medicare Centre
- H4 - Tan Tock Seng Hospital
- H5 - Novena Medical Centre
- H6 - Kwong Wai Shiu Hospital and Nursing Home



Eldercare - Respite Care

- EC1 - Orange Valley Care Centre (Balestier)
- EC2 - Community for Successful Ageing (ComSA@Whampoa)
- EC3 - HWA Whampoa Rehabilitation Centre
- EC4 - St Luke's ElderCare Whampoa Centre
- EC5 - Active Global Specialised Caregivers Singapore



Senior Activity Centre

- SAC1 - NTUC Health Senior Activity Centre
- SAC2 - Kwong Wai Shiu Activity Center



24-Hour Family Clinic @ Thomson Medical Centre



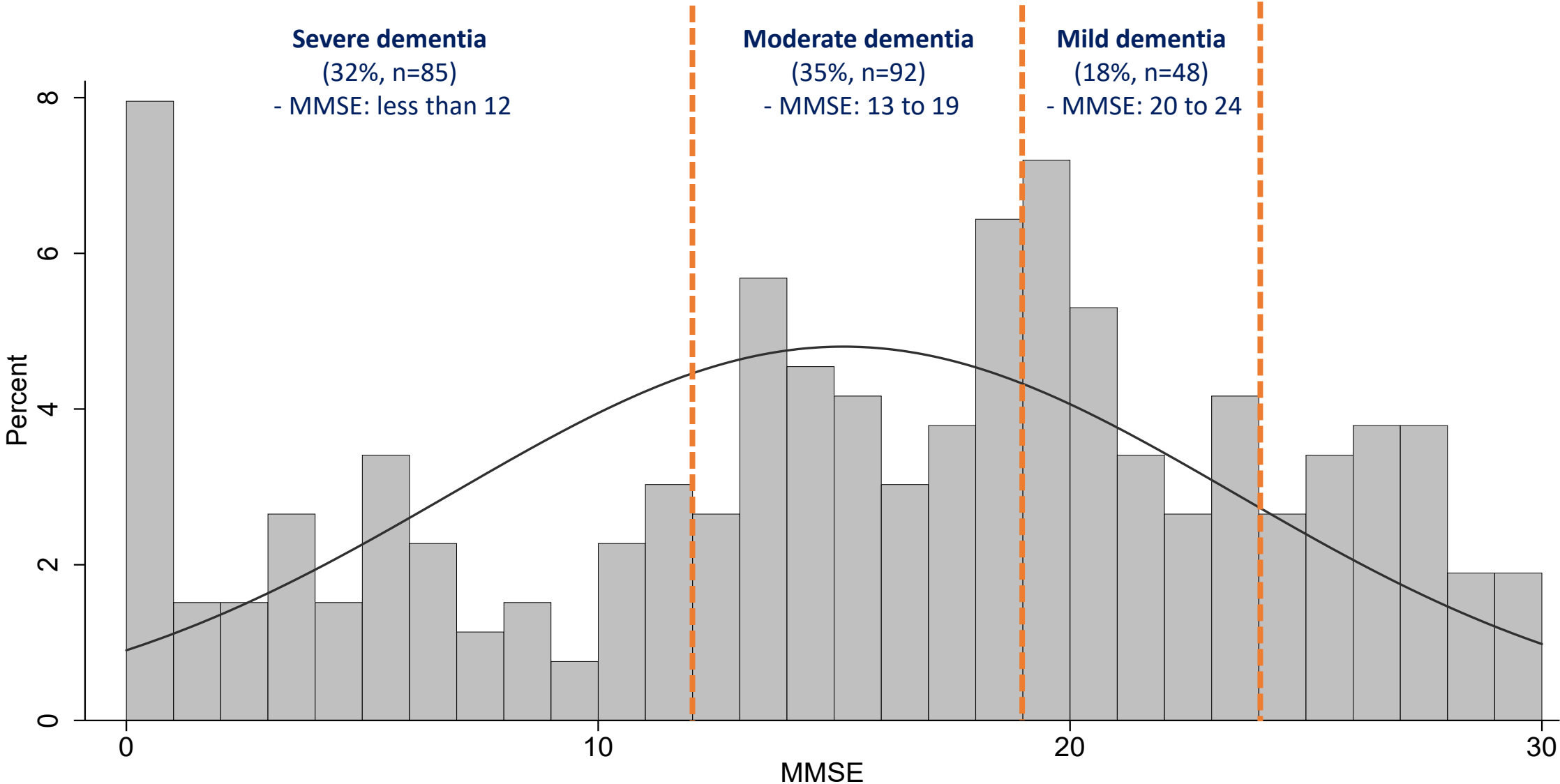
Whampoa Family Service Centre

Results

Community Needs Assessment Survey

- 3,589 older adults (60+) in Whampoa community were screened.
- 323 individuals had AD8+MMSE(2) scores less than 8
- 266 individuals and their caregivers agreed to study
- 266 dyads completed the demographic and needs assessment surveys (PWD and caregiver, separate questionnaires)

Distribution of MMSE (N=264)



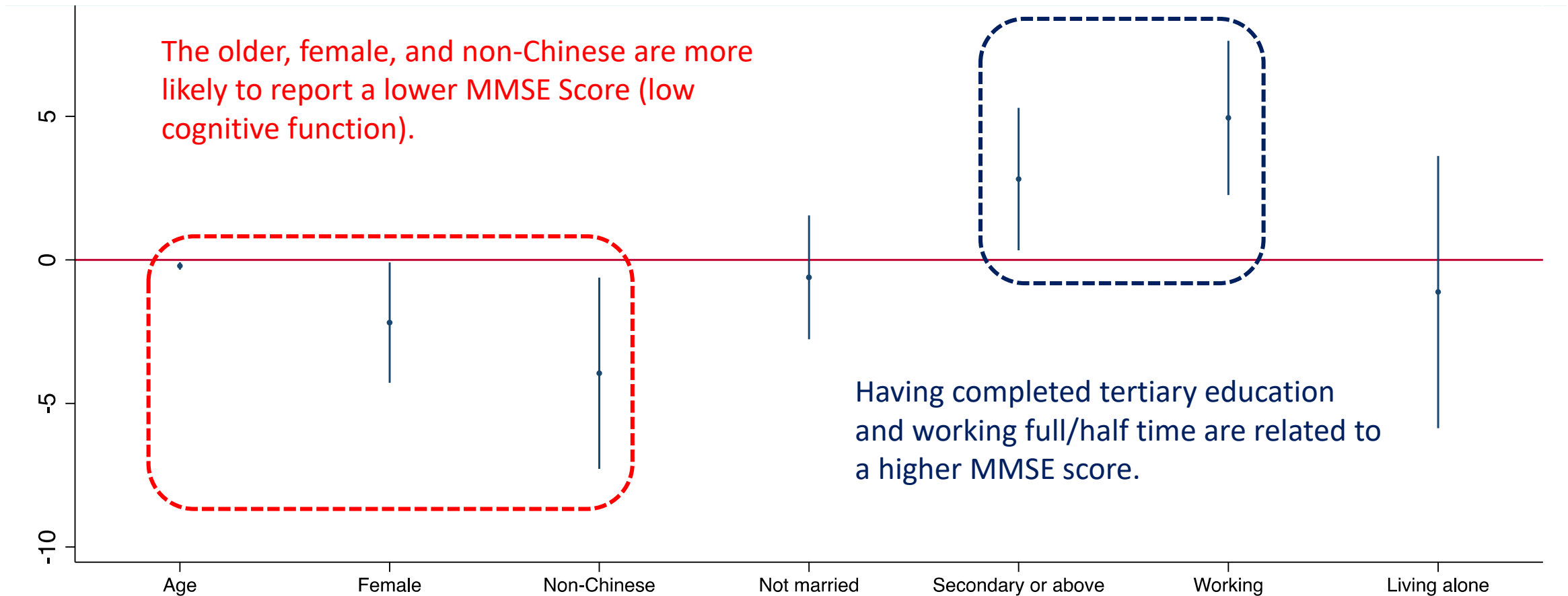
Profiles of Persons with Dementia (N=266)

	N	Mean (%)
Age (60-104)	266	81
Gender		
Men	114	43%
Women	152	57%
Ethnicity		
Chinese	241	91%
Non-Chinese	25	9%
Marital status		
Married	126	47%
Widowed	117	44%
Separated/Divorced/Never married	23	9%
Education		
No formal education	125	48%
Lower primary/primary	86	33%
Lower secondary and above	55	19%

	N	Mean (%)
Employment status		
Working	12	5%
Not Working	254	95%
Housing		
HDB/JTC (1-2 room)	31	12%
HDB/JTC (3 room)	127	48%
HDB/JTC (4+ room)/other type	107	40%
Living arrangement		
Alone	13	5%
With family members	177	67%
With non-family members	76	29%

Predictors of MMSE (N=264)

Mean MMSE (0-30): **15.4 (moderate dementia)**



Unstandardized coefficients with 95% CI shown

Profiles of Caregivers

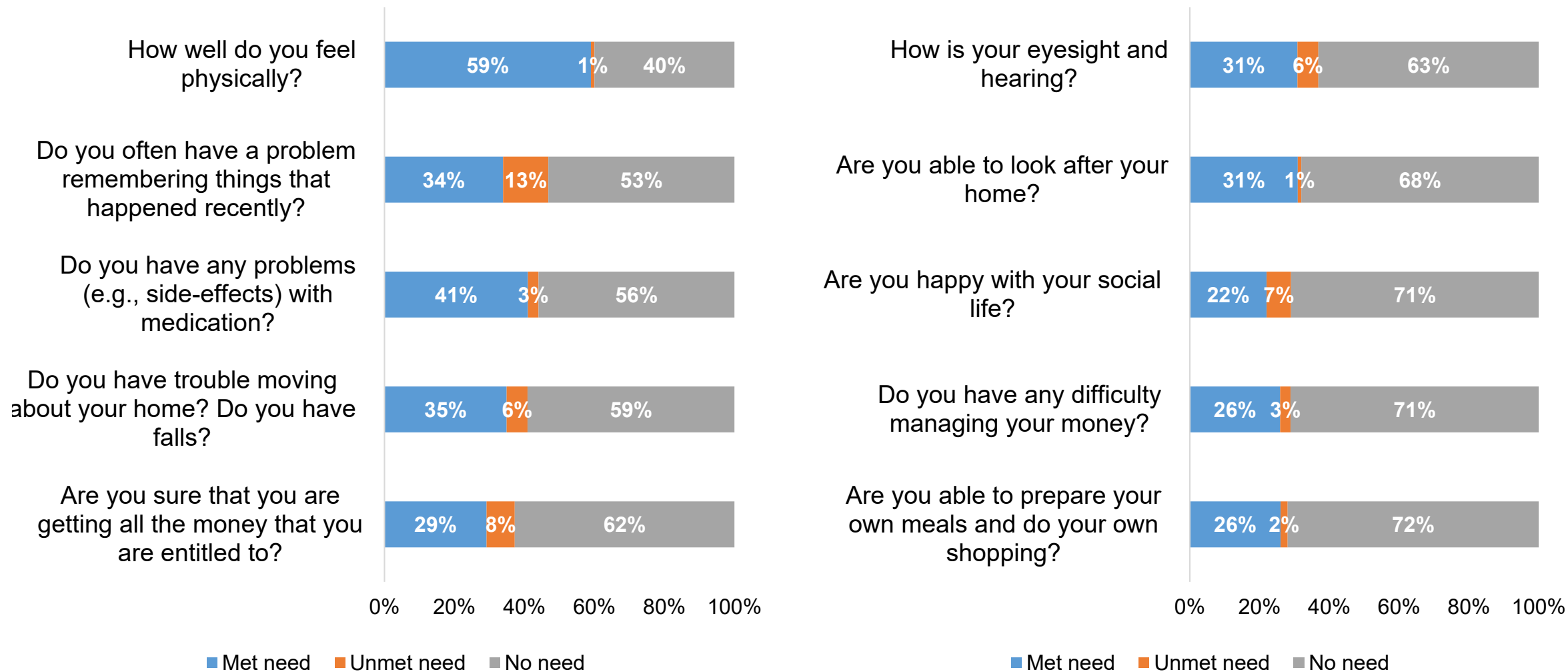
	N	Mean (%)
Age (23-93)	266	63
Gender		
Men	108	41%
Women	158	59%
Ethnicity		
Chinese	240	91%
Non-Chinese	26	9%
Marital status		
Married	172	65%
Widowed/Separated/Divorced	26	10%
Never married	68	25%
Education		
No formal education	39	15%
Some primary	58	22%
Some secondary	104	39%
Tertiary	65	24%

	N	Mean (%)
Employment status		
Working	118	44%
Not Working	148	56%
Financial resources		
Adequate/More than adequate	137	52%
Occasionally adequate	75	29%
Usually inadequate	51	19%
Relationship to Care Recipients		
Spouse	90	34%
Children	137	51%
Others	39	15%

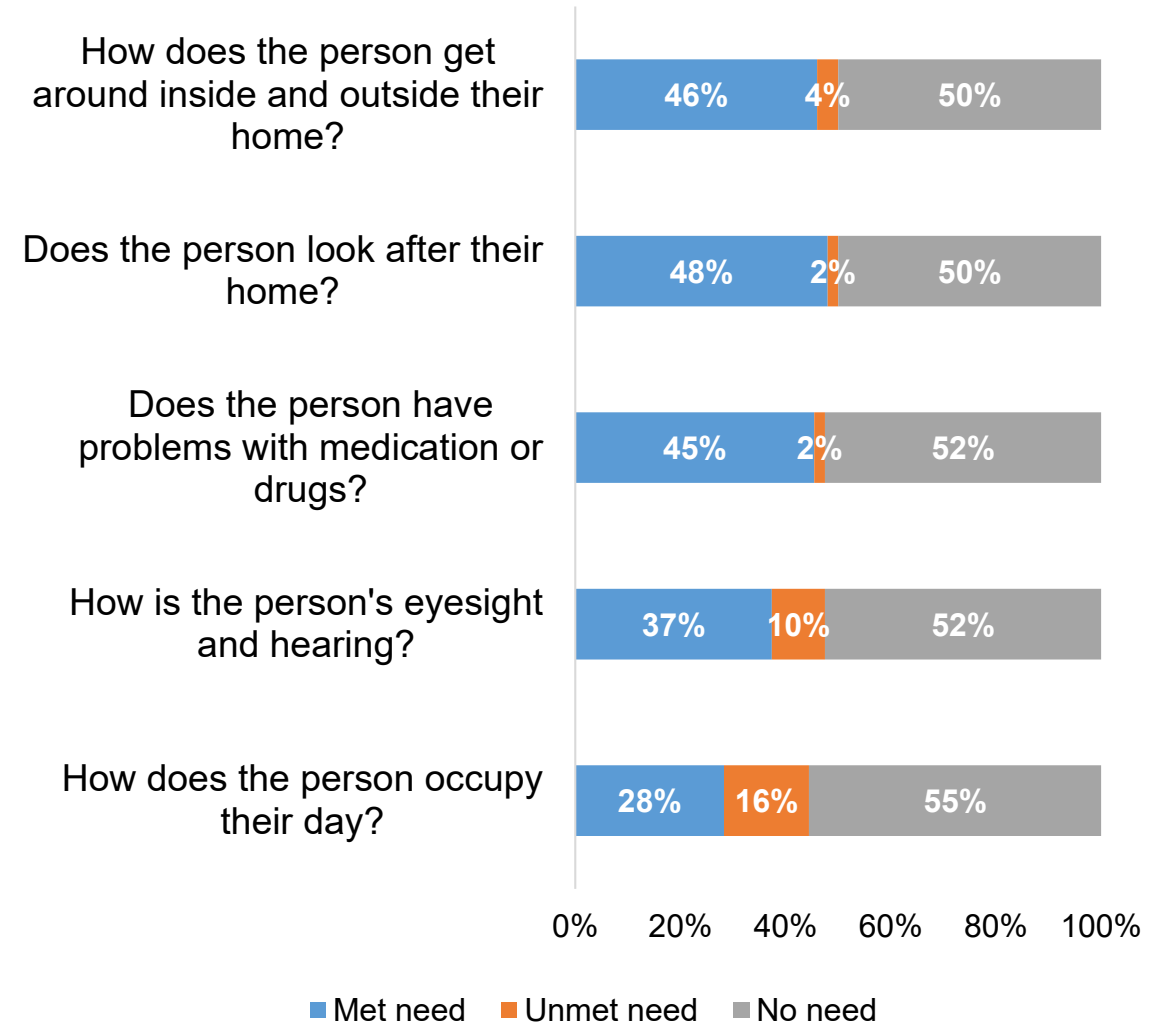
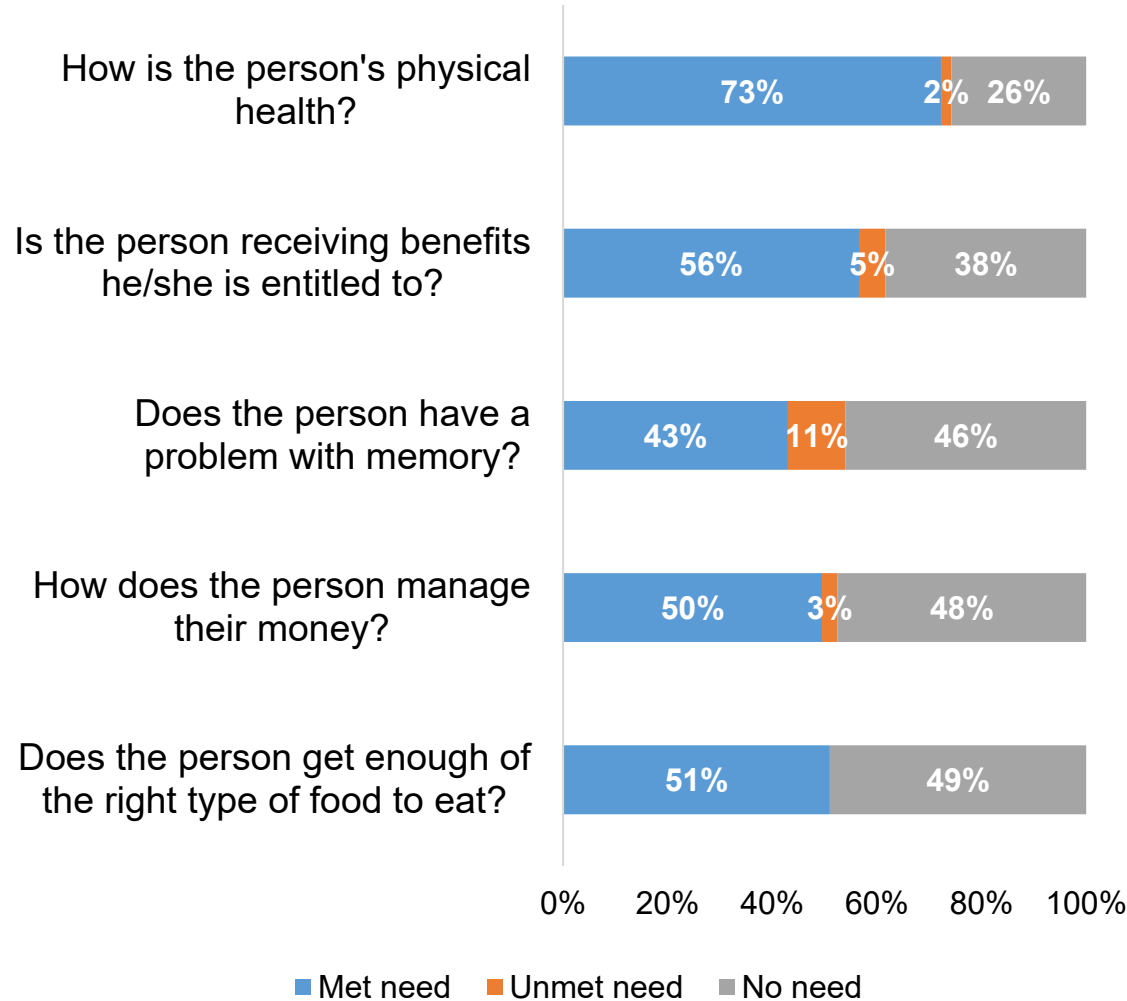
Needs of Persons with Dementia

- A 24-item Camberwell Assessment of Need for the Elderly (CANE) evaluates environmental, physical, psychological, and social needs of care recipients.
 - Does the person have an appropriate place to live?
 - How is the person's physical health?
 - Does the person have problems with mood or anxiety?
 - Does the person have a close emotional/physical relationship?
- Response categories:
 - Met need
 - Unmet need
 - No need

Top 10 needs reported by PWD (n=135)



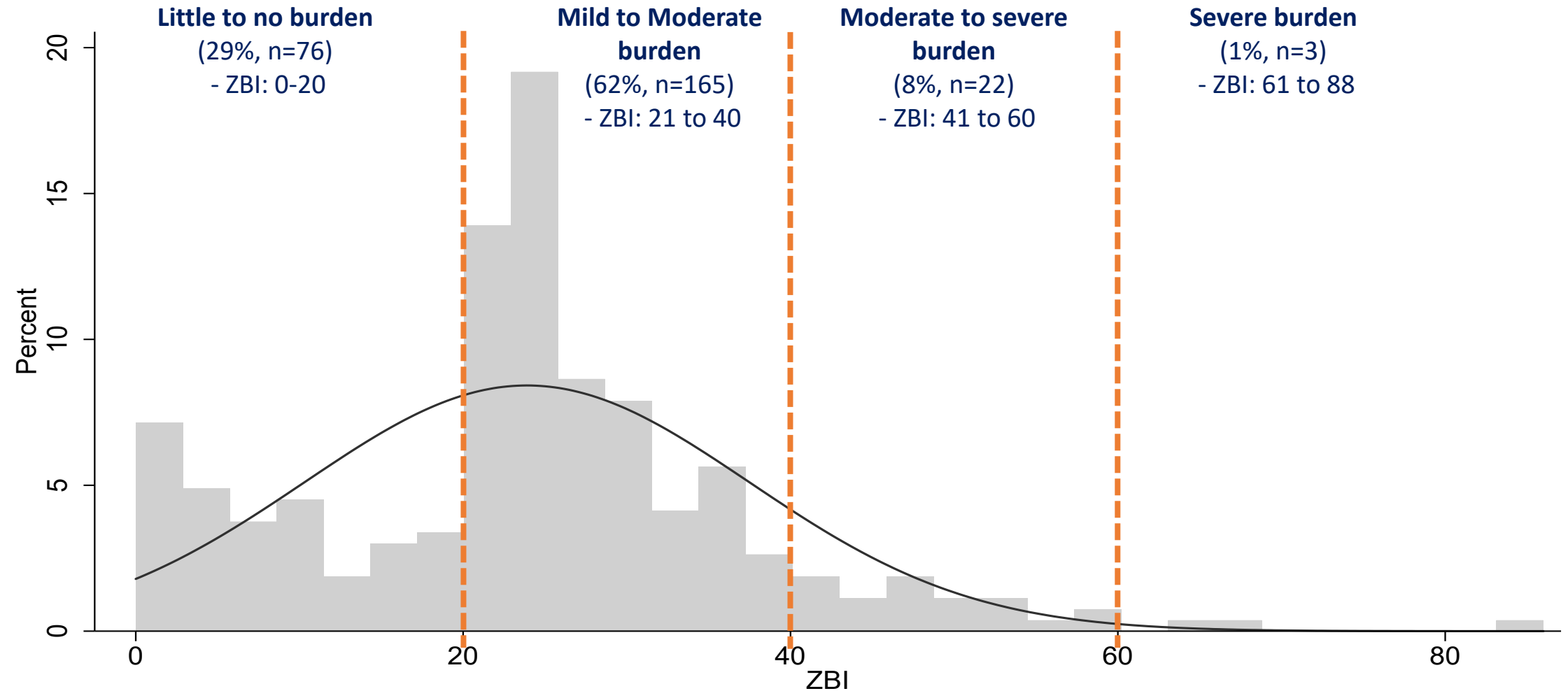
Caregiver reporting of top 10 needs of PWD (n=266)



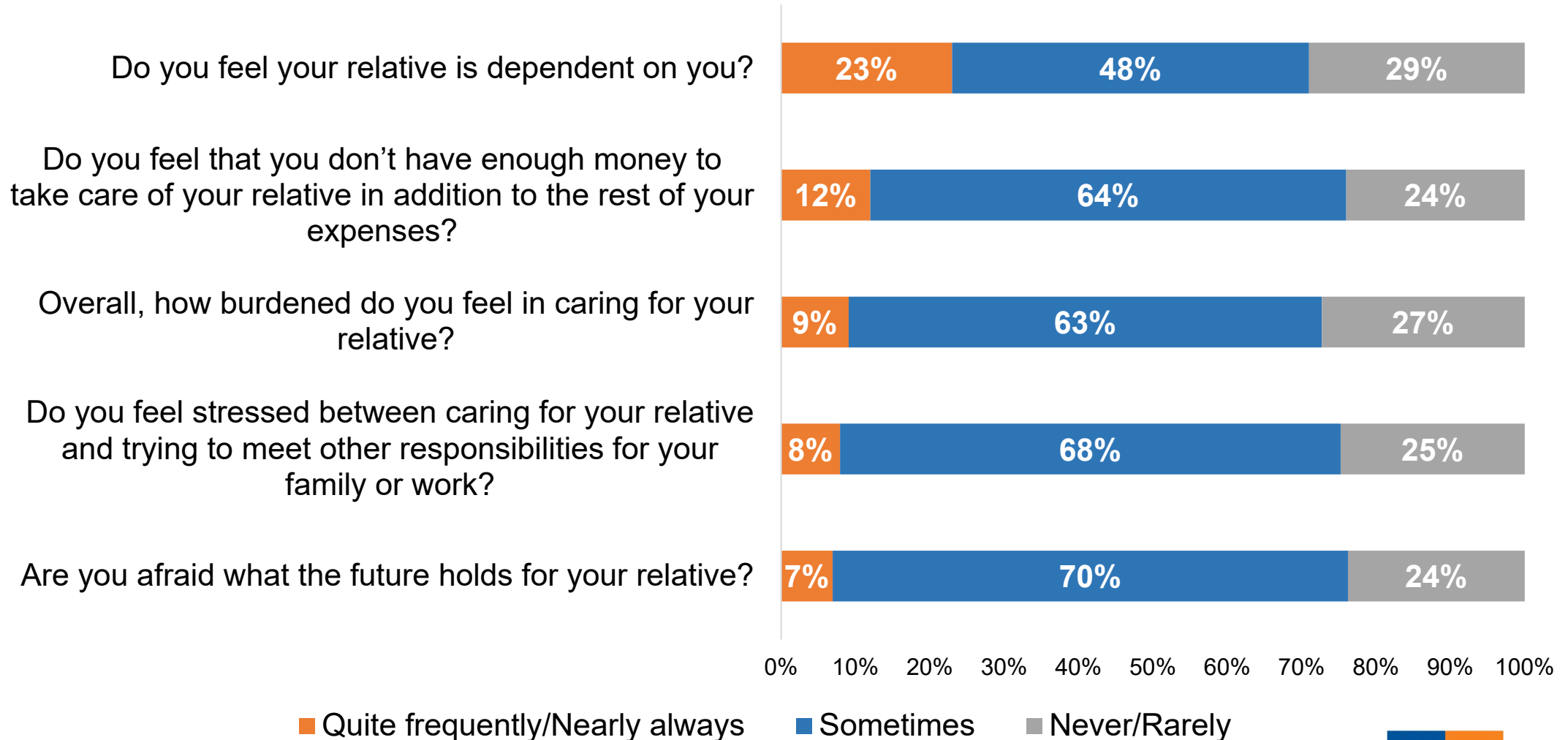
Zarit Burden Interview (ZBI)

- Measures caregiver health and well-being, finances, social life and their relationship with care recipients (22 items)
 - Do you feel your relative is dependent on you?
 - Do you feel that you don't have enough money to care for your relative?
 - Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
- Response categories (0-4):
0=never; 1=rarely; 2=sometimes; 3=quite frequently; 4=nearly always
- Score <24 identifies caregiver at risk of depression

Distribution of ZBI scores (n=266)



Caregivers burdened due to care responsibilities, finances, work-life balance, the future....



Summary of needs assessment survey

- 68% of community-dwelling PWD have moderate or severe dementia
- On average, PWDs:
 - 81 years old
 - Female
 - Live with family
 - 5% live alone
 - No formal education
- Caregivers do not report large percentage of unmet needs in survey format
 - Largest unmet need = how to help PWD occupy their day
- Higher caregiver burden related to caregiving responsibilities, finance, work-life balance, and concerns about the future

Qualitative findings more elaborate and detailed

- **Memory and behaviour problems strained communication and lowered caregiver emotional well-being**

- “When he’s not attentive, I have to say many times. And sometimes I end up scolding him loudly, and I feel bad.”
- “I have to show her [how to get from home to an activity centre] at least another 23 more times. That sort of stress. You know, they just don’t understand, and she will argue. I don’t have the patience to talk to her for an hour, you know? I’m also busy with work everyday.”

- **Challenging behaviour (night-time activity, wandering, violence)**

- “She was very violent at night... From 12 all the way until 7am. We cannot sleep, she will make a lot of noise, shout here, shout there. So we felt very stressed, then don’t know how...”
- “Sometimes she pass motion, and we can smell but she will deny you know, she has that kind of dignity in her...that’s why she fell, when she can’t walk, I came in and saw her hit her head on the wall because she was very determined to get up”

Qualitative findings detail aspects of caregiver burden in more detail

- **Lack of knowledge on how to provide dementia-specific care for PWDs**
 - “A bit disoriented, don’t know what to do and don’t know what’s the next step... I more like move along with it, certain things I don’t want to think sometimes”
- **Negative impact on caregivers own health and social wellbeing**
 - “[Caregiving] is tiresome, very tough, my spine is crooked, and cartilage is worn out. I have problem now to change her diapers because her leg can’t even move up... I quarrel with her all day... it is bad if your blood pressure is high. I often feel a bit depressed. My stress is very great”
 - “Last time I join my friends for yoga sessions, but stop long ago [to take care of my dad]”
- **Strain of juggling caregiving, employment, finances, and other family responsibilities**
 - “I gave up my job [to take care of my mother] because she does not want to employ a helper, she also doesn’t like to go nursing home. So the most effect on me is that I have no income, but I also have no choice.”

Phase II: Pilot Dementia Care Model Evaluation (Interim findings)

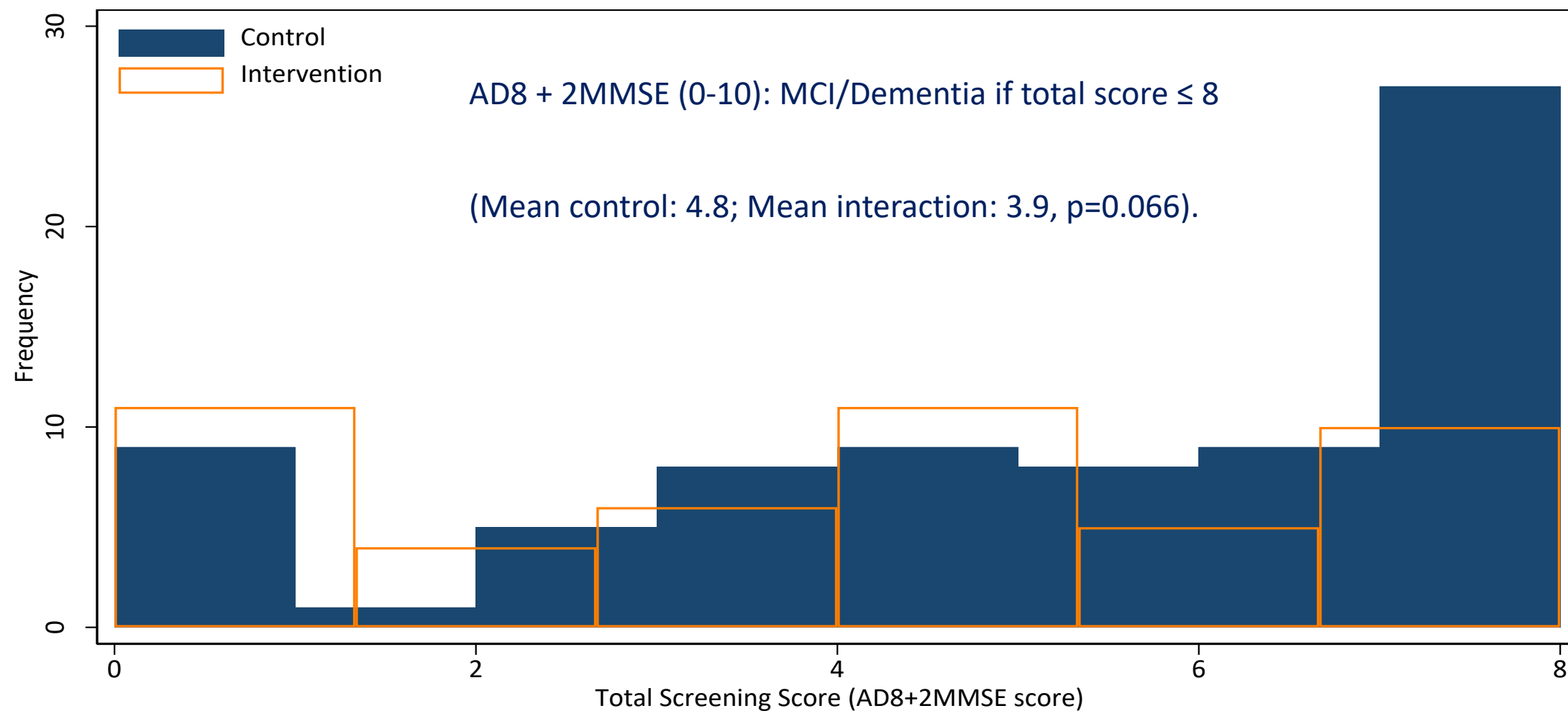
Intervention results

- Interim data for 47 intervention and 76 control dyads
- 6-8 month outcomes from intervention and control groups compared to assess if Dementia Care System programme participants had:
 - A slower rate of cognitive decline
 - Reduction in memory and behavioural problems
 - Reduction in caregiver stress and burden
 - Better health-related quality of life

No significant differences between intervention and control participant demographics

	Controls		Intervention		T-test
	N	Mean (%)	N	Mean (%)	
Age	76	82 years	47	82 years	C=I (p=0.61)
Gender					
Women	76	59%	47	55%	C=I (p=0.67)
Ethnicity					
Chinese	76	96%	47	91%	C=I (p=0.29)
Marital status					
Married	76	50%	47	49%	C=I (p=0.91)
Education					
No formal education	73	41%	46	59%	C=I (p=0.06)
Employment status					
Employed	76	7%	47	2%	C=I (p=0.27)

Although lower, AD8+2MMSE scores for intervention group not significantly different from control



MMSE scores of intervention and control participants remained the same at follow-up

MMSE (0-30)	Control (N=76)	Intervention (N=47)	Difference (I-C)	Robust SE	T-test (two-tailed)
At baseline (T0)	15.17	12.66	-2.51	1.49	C = I ($p=0.094$)
At 6-month follow-up (T1)	13.50	10.51	-2.99	1.54	C = I ($p=0.053$)
Difference (T1-T0)	-1.67*	-2.15*	-0.48 (DID ^a)	2.14	$p=0.824$

- **The Difference in Difference (DID)** estimator (T1 difference – T0 difference) tests if and to what extent the intervention influences the expected change in outcomes over time in the control group
- Despite the deterioration in cognitive function in 6 months for both intervention and control groups, no between-group differences were identified at baseline and follow-up.

The DCS program did not impact RMBPC scores

RMBPC (0–96)	Control (N=76)	Intervention (N=47)	Difference (I-C)	Robust SE	T-test (two-tailed)
At baseline (T0)	14.04	20.15	6.11*	2.38	$C < I$ ($p=0.011$)
At 6-month follow-up (T1)	14.96	19.80	4.84*	2.12	$C < I$ ($p=0.023$)
Difference (T1–T0)	0.92	-0.35	-1.27 (DID)	3.19	$p=0.691$

- CG from the intervention group reported higher memory and behavioral problems of their CR than CG from the control group at baseline.
- A similar pattern was identified after 6 months, which suggests that the intervention may have a limited impact on CRs' memory and behavioral problems.

ZBI scores increased significantly for the control group

ZBI (0-88)	Control (N=76)	Intervention (N=47)	Difference (I-C)	Robust SE	T-test (two-tailed)
At baseline (T0)	23.95	28.28	4.33*	2.16	$C < I$ ($p=0.046$)
At 6-month follow-up (T1)	27.22	29.45	2.22	2.10	$C = I$ ($p=0.290$)
Difference (T1-T0)	3.27**	1.17	-2.11 (DID)	3.01	$p=0.484$

- We observed a significant difference between intervention and control groups at baseline: a higher level of caregiver burden among the intervention compared to the control.
- Interestingly, the difference disappeared at 6 months follow-up: while caregiver burden was increased for the control group, it remained same for the intervention group.

Qualitative findings highlight areas where the DCS programme has helped with PWD memory and behaviour problems

Types of memory and behaviour problems reported		Impact of intervention	
<ul style="list-style-type: none">Perceived deterioration of PWDs' cognitive function led to difficulties in communication that imposed a strain on the dyads' relationshipsForgetfulness of PWD caused frustration and distress in caregivers; lowered their emotional wellbeing	<p>"When he's not attentive, I have to say many times. And sometimes I end up scolding him loudly, and I feel bad."</p> <p>"I have to show her [how to get from home to an activity centre] at least another 23 more times. That sort of stress. You know, they just don't understand, and she will argue. I don't have the patience to talk to her for an hour, you know? I'm also busy with work everyday."</p>	Psychoeducation on dementia facilitated communication between caregiver and PWD.	"We are educated about dementia, so we try to give him a routine, we know his needs, and we are careful with the way we talk to him."
<ul style="list-style-type: none">Challenging behaviourDisrupted sleep and night-time activity, wandering and getting lost, incontinence, threatening speech, violent actions, and self-harm	<p>"She was very violent at night... From 12 all the way until 7am. We cannot sleep, she will make a lot of noise, shout here, shout there. So we felt very stressed, then don't know how..."</p> <p>"Sometimes she pass motion, and we can smell but she will deny you know, she has that kind of dignity in her...that's why she fell, when she can't walk, I came in and saw her hit her head on the wall because she was very determined to get up"</p>	<p>Improvements in behaviour of CR after engagement through centre-based physiotherapy and music therapy; home-based cognitive stimulation (music and art-based activities)</p> <p>Benefits of person-centred care that emphasizes empathetic approaches and "dignity-preservation"(for persons with dementia</p>	<p>"a lot of different activities for her... when she comes back, she will feel better, sleep better"</p> <p>"she doesn't like to talk to people, so no interaction with outsiders. But this Auntie [from Hua Mei] coming every Thursday, play game with her. She is quite welcoming and she can accept it and still enjoy... it [her mood and behaviour] improved"</p>

Qualitative findings express how DCS programme has supported caregivers

Types of caregiver burden reported		Impact of intervention	
• Stress from the lack of knowledge on how to provide dementia-specific care for PWDs	“A bit disoriented, don’t know what to do and don’t know what’s the next step... I more like move along with it, certain things I don’t want to think sometimes”	Helplines providing multifaceted support (e.g. medical, social care, emotional support)	“There’s a social worker and a nurse. If it’s a medical issue, I will text the nurse. Anything else I will text the other. When my dad went missing, I’ve been texting them. They are supportive and respond very fast”
• Adverse impact of caregiving on caregiver’s own health and social wellbeing	<p>“[Caregiving] is tiresome, very tough, my spine is crooked, and cartilage is worn out. I have problem now to change her diapers because her leg can’t even move up... I quarrel with her all day... it is bad if your blood pressure is high. I often feel a bit depressed. My stress is very great”</p> <p>“Last time I join my friends for yoga sessions, but stop long ago [to take care of my dad]”</p>	Provision of more accessible medical care to caregiver allows for greater self-care	“When they come to visit my husband, the nurse also take my BP everything, help me, check my medicine, everything... Polyclinic so far, now here got clinic (at Whampoa CC), better go straight here”
• Strain of juggling caregiving, employment, finances, and other family responsibilities	“I gave up my job [to take care of my mother] because she does not want to employ a helper, she also doesn’t like to go nursing home. So the most effect on me is that I have no income, but I also have no choice.”	Social care and assistance with applications for subsidies and financial help	“This [application for medical subsidy], I don’t know how to... if I fill up wrongly, I cannot pass. That’s why I very scared. Never mind, they [social worker] always come”

Summary of interim results

- No significant differences between intervention and control groups at 6 month follow-up for:
 - MMSE scores
 - RMBPC scores
 - HRQOL
- However, control group reported a significant increase in ZBI scores over time (no change for intervention group)

Conclusion

- While identification of persons with dementia in the community is feasible, it is difficult to recruit families into the intervention
- Study needed to recruit from existing clinic patients
- Intervention results indicate a need to tweak the programme further
- More specific training is required for specific skills (dementia care, geriatric medicine, psychoeducation, social care, counselling)

Intervention challenges

- Staffing issues in delivering care to community-dwelling PWDs
 - Recruitment and retention difficulties
 - Extensive training required for specific skills (dementia care, geriatric medicine, psychoeducation, social care, counselling)
- More targeted services needed for different client archetypes
 - Archetype 1 – PWDs lacking cognitive engagement
 - Archetype 2 – PWDs with significant behavioural problems
 - Archetype 3 – PWDs with limited social support
 - Archetype 4 – Newly diagnosed with dementia

Archetype 1: PWDs lacking cognitive engagement

Caregiver relationship (no. of dyads)	No. of intervention dyads	Characteristics	Unmet needs reported (Quantitative)	Unmet needs reported (Qualitative)	Targeted services required
<ul style="list-style-type: none"> • Daughter (8) • Son (10) • Wife (3) • Daughter-in-law (1) • Brother-in-law (1) 	23	<ul style="list-style-type: none"> • PWD's ADL needs are generally met but requires more IADL support (i.e. communication management, mobility within community, and taking prescribed medication) • Lack of cognitive stimulation lowers PWD's psycho-emotional wellbeing • CG's psycho-emotional wellbeing also adversely impacted as a result 	<p>Daytime activities – Inadequate social or leisure activities (n=7);</p> <p>Company – Frequently feels lonely and isolated (n=7);</p> <p>Memory – Clear deficit in recalling new information; loses things, becomes disoriented in time and/or place, not receiving appropriate assistance (n=6);</p> <p>Drugs – Dependency or misuse of drugs (n=4);</p> <p>Intimate relationships – Desperately lonely and lacking a confidant (n=2);</p> <p>Eyesight/ hearing/ communication – A lot of difficulty seeing or hearing, does not receive appropriate assistance deficit in recalling information (n=2)</p>	<ul style="list-style-type: none"> • Unsuitable for day care due to CR's communication difficulties, personality, CG/CR care preferences, location of day care/activity centre • Medication compliance and adherence • PWD needs to be engaged in more non-sedentary activities 	<ul style="list-style-type: none"> • Dementia day care • Respite care • Escort • Home-based cognitive stimulation activities • Psychoeducation

Archetype 2: PWDs with significant behavioural problems

Caregiver relationship (no. of dyads)	No. of intervention dyads	Characteristics	Unmet needs reported (Quantitative)	Unmet needs reported (Qualitative)	Targeted services required
<ul style="list-style-type: none"> • Daughter (7) • Son (4) • Wife (4) • Husband (2) • Grandson (1) • Daughter-in-law (1) 	19	<ul style="list-style-type: none"> • PWD is ambulant • Resists care • Demands attention from caregivers • Behaviour may be harmful to themselves and to caregivers 	<p>Daytime activities (n=7);</p> <p>Company (n=7);</p> <p>Money/budgeting – Often has no money for essential items/bills and unable to manage finances (n=2);</p> <p>Eyesight/hearing/ communication (n=2);</p> <p>Memory (n=2);</p> <p>Mobility/falls – very restricted mobility, frequent falls (n=2)</p>	<ul style="list-style-type: none"> • Physical and cognitive engagement • CGs struggle to manage employment and caregiving responsibilities • Assistance with enrolment into care programmes 	<ul style="list-style-type: none"> • Occupational therapy • Physiotherapy • Ad-hoc and extended respite care • Full-time domestic helper • Door-to-door transportation • Psychoeducation • Counselling

Archetype 3: Dyads with limited social support

Caregiver relationship (no. of dyads)	No. of intervention dyads	Characteristics	Unmet needs reported (Quantitative)	Unmet needs reported (Qualitative)	Targeted services required
<ul style="list-style-type: none"> • Daughter (5) • Wife (3) • Husband (3) • Son (2) • Niece (2) 	15	<ul style="list-style-type: none"> • Dyads lacking support from socio-familial relationships (eg: incarceration of adult children, strained relationships with in-laws) • Complex family dynamics • CGs unable to provide physical support due to health conditions (eg: weakness/pain in legs due to worn cartilage) • Includes frail caregivers 	<p>Daytime activities (n=4); Intimate relationships (n=3); Company (n=2); Behaviour – Recent experience of violence, threatening or seriously disruptive behaviour (n=2); Continence – Regularly wet or soiled. Deteriorating incontinence (n=1); Memory (n=1); Eyesight/ hearing/ communication (n=1)</p>	<ul style="list-style-type: none"> • Help with domestic chores (cleaning, grocery shopping) • Financial support / assistance with applications for support schemes • Anxiety over end-of-life issues • Emotional support • Long-term care plans that maintains relationship between spouses • PWDs requiring assistance with ADLs 	<ul style="list-style-type: none"> • Social care advocate and case management • Home health care and personal care for both CG and PWD • Helplines for emotional support and practical advice on daily care provision or emergencies • Counselling

Archetype 4: Newly diagnosed with dementia

Caregiver relationship (no. of dyads)	No. of intervention dyads	Characteristics	Unmet needs reported (Quantitative)	Unmet needs reported (Qualitative)	Targeted services required
<ul style="list-style-type: none"> • Daughter (3) • Son (1) 	4	<ul style="list-style-type: none"> • PWD in early stages of dementia • PWD, CG, family members lack understanding of disease trajectory 	<p>Continence (n=1);</p> <p>Psychological stress - Distress affects life significantly, e.g., prevents person from going out (n=1)</p>	<ul style="list-style-type: none"> • CGs inadequately prepared to cope with PWDs' changes in behaviour (e.g. lacking information on wandering and getting lost) • Communication difficulties between PWD and CGs cause relationship strain (e.g. CGs experience frustration with PWDs' forgetfulness) 	<ul style="list-style-type: none"> • Case management and social care • Peer support • Counselling and psychoeducation for dyad to learn how to cope with diagnosis • Drafting of LPAs and ACPs before severe cognitive deterioration occurs

Next steps

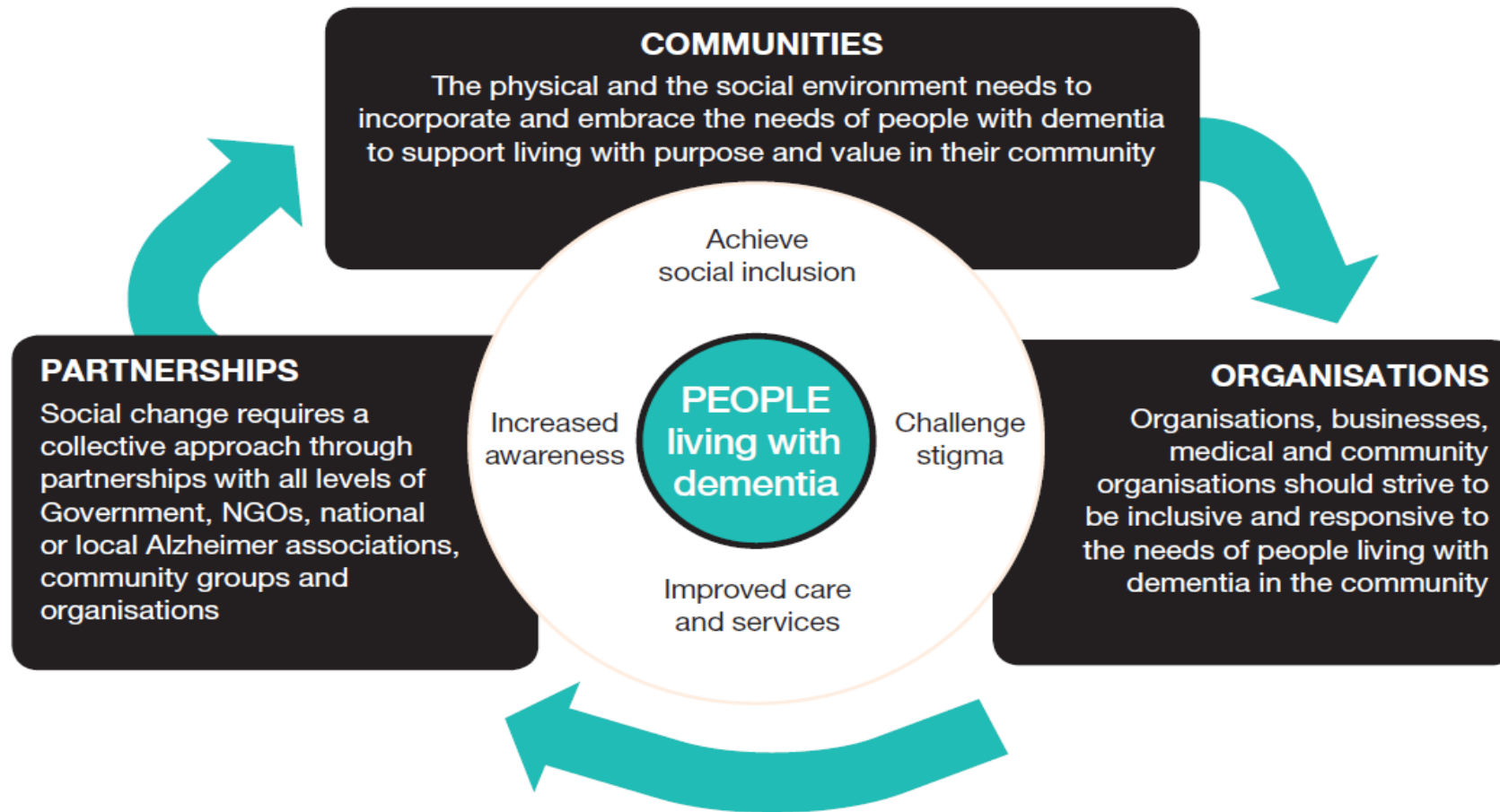
- Completion of follow-up interviews with intervention dyads
- Final evaluation of DCS
 - Integrate quantitative and qualitative findings of programme impact and challenges
 - Cost-Effectiveness Analysis of DCS
- Evaluation of cognitive training programme
- Development of blueprint for community-based interdisciplinary dementia care

Dementia-Friendly Communities

WHO global action plan on the public health response to dementia 2017-2025 aims to improve the lives of PWDs, their carers and families, while decreasing the impact of dementia on communities. It targets 7 areas:

- Dementia as a public health priority
- Dementia awareness and friendliness
- Dementia risk reduction
- Dementia diagnosis, treatment, care and support
- Support for dementia carers
- Information systems for dementia
- Dementia research and innovation

Principles for Dementia Friendly Communities



Source: Alzheimer's Disease International. *Dementia Friendly Communities: Key Principles* (<https://www.alz.co.uk/adi/pdf/dfc-principles.pdf>)

Dementia Friendly Communities

Primary Outcome	Type of Activity
Awareness	<i>Dementia Friends</i> national initiatives with basic training to promote a greater awareness of dementia among large numbers of people (Canada; Japan; UK – England, Scotland and Wales)
Social and cultural engagement	<ul style="list-style-type: none"> - Establishment of local alliances to implement dementia friendly communities involving people with dementia and family carers. (Japan, US, UK, Australia) - Local social engagement through Alzheimer/Dementia/Memory Cafés (introduced in the Netherlands and now established in many other countries) - Buddy programmes to support people with dementia in voluntary or paid employment or in access to sports programmes (Ireland; Netherlands; Australia; Japan) - Transportation services to respond to the special needs of people with dementia (USA; Liverpool, UK – England)
Human rights	Providing a right to a service, for example a right to a timely diagnosis (UK) and a guarantee of post diagnostic support for 12 months to those newly diagnosed (UK – Scotland)
Capability building and access to services	<ul style="list-style-type: none"> - Training and education resources and programmes (e.g. Dementia Friendly America) - Promoting access to services nationally through major networks such as banking or retail (Taiwan; Netherlands; UK)
Physical environment	Providing best practice design for domestic and residential dementia care (New Zealand; Australia; Norway)

Case Study: Japan

The New Orange Plan launched by the Japanese government in 2015 represents a multisectoral collaborative effort amongst 12 ministries and agencies. The main objectives are:

- **Coordination of medical and long-term care**
 - Early support: establish geriatricians and long-term care specialists in all municipalities.
 - Improving care providers' capacity: engage 75,000 primary care doctors in training and capacity building for responding to dementia
 - Coordination of medical and long-term care: dementia coordinators are established in all municipalities.
- **Research for prevention and cure**
 - Prevention: 10,000 people to participate in nationwide prospective dementia cohort study aimed at identifying risk and protective factors, and establishing prevention in the community.
 - Project for Psychiatric and Neurological Disorders to conduct clinical trials of drug candidates originating in Japan for dementia treatment.
- **Age- and dementia-friendly community**
 - Dementia supporters: training 12 million dementia supporters with good knowledge and understanding of dementia (e.g. LemonAid)
 - Safety: establish cross-ministerial support such as community watch system, and protection against consumer fraud