

# Delivering a holistic hospital-to-home framework to support family caregivers of persons with dementia: Protocol for a feasibility study

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## Abstract

**Aim:** To evaluate the feasibility of the Carer Matters holistic hospital-to-home framework for family caregivers of people with dementia.

**Background:** Family caregivers of persons with dementia face a unique blend of stressors, from behavioural management to navigating the healthcare system. It is important to provide support and assistance to help caregivers cope to enable a sustained capacity for caregiving. This led to our establishment of Carer Matters, the first holistic caregiver-centric hospital-to-home framework of support for caregivers of persons with dementia in Singapore.

**Methods:** A multimethod study design will be used. We will assess the programme's feasibility and effectiveness using a Theory of Change approach, with findings synthesized using the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework. Our study will involve six inpatient wards of a 1700-bedded acute care hospital over 12 months. Qualitative data will be obtained from interviews of stakeholders—caregivers, healthcare professionals, hospital leaders and community leaders. Quantitative data will be collected from programme logs, surveys and evaluation forms that capture self-reported levels of mastery, anxiety, burden, and depression. Funding has been approved by the Geriatric Education and Research Institute (GERI) Intramural Project Grant (GERI Ref: GERI1626) on May 2020 for this study (£103,659), to be conducted from December 2020 to June 2022.

**Discussion:** The stresses faced by caregivers of persons with dementia are wide and complex, necessitating a multi-faceted caregiver-oriented solution to provide sustained support, empower better management and continued capacity to care. Our study would provide insights on the feasibility and effectiveness of a caregiver-centric support programme stretching from the hospital into the community.

**Impact:** These findings will provide a blueprint on how to implement a hospital-to-home patient-caregiver framework and provide policymakers, clinicians, and advocacy groups with critical insights on the potential patient-caregiver-healthcare system outcomes that can be derived.

## KEYWORDS

burden, caregiver, caregiving stress, continuity of patient care, dementia, feasibility studies, nursing, older person, screening tool, Singapore

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## 1 | INTRODUCTION

“Blood is thicker than water”. The adage of the strength of family bonds in times of trouble often compels family members to become the first line of care delivery to older persons in need, helping them age in place at home (Lau et al., 2021; Lim et al., 2011; Thomas et al., 2017). This can lead to caregivers facing a multi-faceted range of stressors as they manage the needs of their loved one while juggling their own roles and responsibilities as working adults and over their own households (Thai et al., 2016).

The difficulties faced by caregivers are especially pronounced when looking after a person with dementia (PwD), struggling to manage the behavioural symptoms experienced by their loved one that could range from disrupted sleep patterns to outbursts of agitation (Ong et al., 2022). Such hardship can be exacerbated by the isolation of the caregiver, as other family members might be unwilling to help distribute their many responsibilities (Chan, Phang, et al., 2019). Without relief, caregivers of PwD are often engulfed by the stressors they face, leading to depression, grief, and anxiety (Thomas et al., 2017). This phenomenon is epitomized in the term “caregiver burden”, an umbrella term that encompasses the negative emotional, physical, practical, and social impacts of caregiving (Lim et al., 2011).

The phenomenon of “caregiver burden” is no stranger to a grey-ing society like Singapore, a developed Asian city-state, where one in four persons will be aged 65 years and over by 2030 and cared for by a shrinking pool of working adult family members (Strategy Group Singapore: Prime Minister's Office, 2020). Caregiver burden remains a major unresolved issue in many family caregivers, many of whom took the role as both a familial and societal expectation of spouses and children looking after their loved ones (Chan et al., 2018). The high stress faced was evident in our earlier interviews of caregivers of PwD, with several relating the incessant grind of responsibilities and management of difficult behaviours as a “mental torture” and a respondent even considering suicide due to the overwhelming stress (Chan, Phang, et al., 2019). If unresolved, such caregiving stress has been shown to translate into increased strain on local healthcare systems as well, with caregivers referring their care recipient for medical management more frequently. This was reflected in a recent study that found that caregiver distress contributed towards emergency room attendance, with caregiver burden being positively associated with care recipients' length of hospital stay (Lau et al., 2021).

The experience of hospitalization and subsequent preparation for discharge remains a stressful period for caregivers, facing the uncertainty of their loved one returning home with potentially higher care needs (Chan et al., 2018; Chan, Phang, et al., 2019). Nurses play a valuable part in the potential identification and escalation of support for a stressed caregiver, as nurses are the main point of contact between the hospital and caregivers in the conduct of training and other skills-preparation programmes. This is most evident in the role of dementia case managers, nurses who take the key role as the ‘main point of contact’ in the needs of the care of a PwD (Iliffe et al., 2014). However, while case managers often consider the needs of a PwD, including their caregiving arrangements, there is

### Summary Statement

- Caregivers of persons with dementia are at increased risk of stress and need support, to help them better cope and thrive together with their care recipient.
- Carer Matters is the first holistic hospital-to-home support programme designed from the ground-up for caregivers.
- This proposed study would provide valuable insights on the feasibility of this programme, guiding clinicians and leaders on its potential for growth and sustainment.

yet to be a capability for nurses to deliver holistic care specifically around caregivers' needs—such as meeting information needs, support wayfinding and managing clinical, emotional, and psychological challenges at home.

Caregivers' needs evolve over time with their journey together with their care recipient, with the hospitalization period requiring them to often acquire needed caregiving knowledge and skills. Hence, it would be opportune to use this period to identify caregivers in need and explore a relationship-based approach to care that seeks to provide continuous engagement and support (Tung et al., 2018). This led to our team establishing the Carer Matters programme in our hospital for family caregivers of PwD.

## 2 | BACKGROUND

Carer Matters is a caregiver-centric ‘Hospital-to-Home’ programme to holistically screen, identify and provide targeted interventions for caregivers of PwD at risk of caregiver burden. This programme brings together nurses, geriatricians, allied health professionals, and social service agencies to work towards improving the wellbeing of caregivers of PwD, enhancing their ability to provide sustained care. Our interventions include psychosocial and emotional preparation of caregivers' mental resilience and long-term engagement initiatives to connect caregivers into an integrated network of peers and community support services.

### 2.1 | Tenets of Carer Matters

Carer Matters is built off two fundamental tenets—(1) embracing a holistic caregiver-centric approach and (2) orientating caregiver training towards mastery-focused equipping.

Many caregivers lack sufficient preparation to take on the caregiving role; this could be attributed to clinicians' strong focus on equipping them to care for their loved one, rather than assessing their readiness and addressing their needs stemming from these new responsibilities (Chan, Phang, et al., 2019; Ong et al., 2022). Carer Matters alleviates this by providing a caregiver-focused programme oriented around the caregivers' needs which complements the

hospital's existing suite of support for the patient. By supporting the needs of both patients and caregivers, this dyadic approach of care delivery lowers caregiving burden and improves the PwD's functional independence. (Lamotte et al., 2017; Moon & Adams, 2013).

Carer Matters also focuses on equipping caregivers with the knowledge and skills to improve their own wellbeing through mastery-based interventions, which are independently and negatively associated with caregiver burden, anxiety, and depression (Chan et al., 2018). By increasing caregivers' perceived locus of control over their lives and caregiving situation, it reduces perceived caregiving burden and anxiety and depressive symptoms (Pearlin & Schooler, 1978).

## 2.2 | Carer Matters interventions

A flowchart of the activities and interventions offered to caregivers is shown in Figure 1. A summary of the interventions—Identify, Screening and Need Assessment, Interventions, Community Partners and Caregiver Support Network—is detailed in Table 1. Carer Matters is designed to recruit and engage interested caregivers during the hospitalization of the PwD. This period provides an opportune time to identify at-risk caregivers and assist in meeting their needs to better enable them to provide care for their loved ones. Through our nurse-initiated and nurse-led programme, caregivers will be supported by a team of caregiver support nurses, applying their range of knowledge and skillsets that would address caregiver enquires and needs in managing the care of their loved one and in their own self-management of their stress.

To achieve this, caregivers are identified by our hospital's ward nurses, who will approach them when they visit the ward (component 1); to complete an online brief needs assessment that evaluates their risk of caregiver stress and the resources and services that they are keen to receive (component 2). The needs assessment is built off a locally validated brief screening tool we developed to screen and stratify family caregivers at risk of negative health outcomes (Chan, Lim, et al., 2019). The tool's inbuilt algorithm tailors their

identified needs against a library of resources available, allowing caregivers access to the appropriate information and resources. This would aid the delivery of resources matchmade to caregivers' needs, allowing a tailored suite of solutions instead of a 'one-size-fits-all' approach (Ong et al., 2022). For instance, caregivers identified to be highly distressed will be promptly contacted and engaged by the hospital's caregiver support nurses for telesupport, to help identify their stressors and activate appropriate hospital and community resources.

Our interventions consist of telesupport, programmes or a combination of both, depending on the assessed caregivers' need. Caregivers identified to be at high risk of stress are offered telesupport by the caregiver support nurses, who are trained with geriatric and counselling skills and knowledge (component 3a). This consists of regular "check-in" telephone calls to the caregivers, providing telecounselling and connecting them to community partners for further support. The delivery of such a 'check-up' was found to be appreciated during our interviews of caregivers of PwD, helping them address any queries they might have had during the hospital stay and providing an avenue for continued engagement with representatives of the hospital (Chan, Phang, et al., 2019).

As part of our skills-equipping and training of caregivers, we offer access to our evidence-based caregiver training programmes (component 3b). These are therapeutic group interventions providing education, support and skills training uniquely designed around the needs of care for a PwD, delivered by the caregiver support nurses. Our programmes are developed around the principles of adult learning, experiential learning, and problem-solving techniques. These programmes involve a combination of simulation and social learning approaches, delivered either in person at the hospital or online. One example of our suite of training programmes is the CARERS programme, originally developed for caregivers of PwD in Canada. CARERS was shown to produce sustained improvement in caregivers' perceived stress, mastery, depressive symptoms, caregiving competence and coping, key qualities needed to support the caregivers' capacity to continue in their caregiving role for the foreseeable future (Sadavoy et al., 2021). When this approach was piloted locally, the caregivers who attended

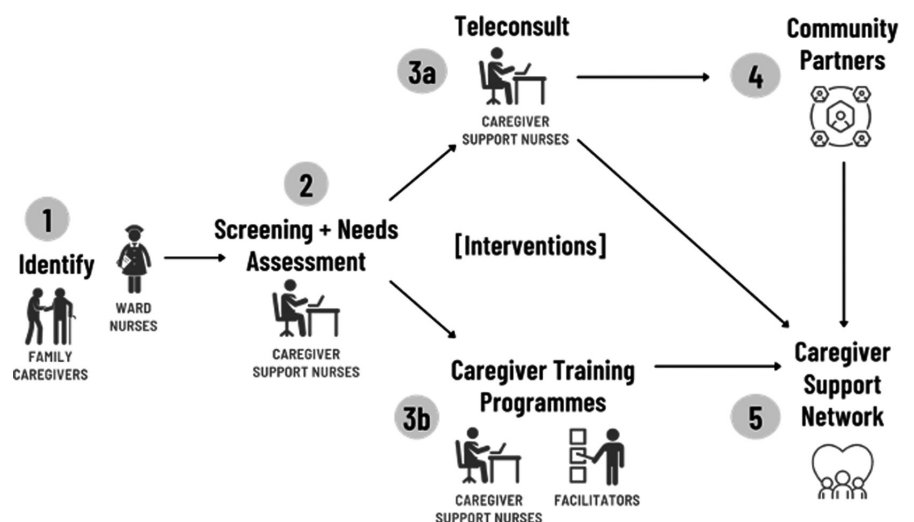


FIGURE 1 Framework of Carer Matters programme

TABLE 1 Summary of activities and interventions applied to caregivers in Carer Matters

Step	Activity/intervention	Goal	Procedures	Provided by
1	Identification of caregivers of eligible hospitalized patients	<ul style="list-style-type: none"> <li>Ensures that eligible caregivers can be enrolled in programme</li> </ul>	<ul style="list-style-type: none"> <li>Ward nurses engage family members of hospitalized patients aged <math>\geq 65</math> years of age</li> <li>Ward nurse enquires if family member is patient's caregiver. If so, describes Carer Matters and directs caregiver to complete needs assessment form by scanning a QR code</li> </ul>	Ward Nurse
2	Screening of needs of caregiver and assessment of risk of stress	<ul style="list-style-type: none"> <li>Allows flagging of highly-stressed caregivers for escalated support</li> <li>Delivers personalized resources to caregivers tailored to their needs</li> </ul>	<ul style="list-style-type: none"> <li>Carer completes online form, consisting of brief screening tool for caregiver stress and list of resources available for them (e.g. financial aids, respite care services)</li> <li>On completion, the algorithm built into the form flags out caregivers whose responses indicate high risk of stress. Stressed caregivers will then be contacted by a caregiver support nurse in seven working days</li> <li>Based on their identified needs, caregivers will also receive tailored support resources via email or text message and recommendations for programmes that can assist them with their caregiving</li> </ul>	Self-completed by caregiver
3a	Telesupport	<ul style="list-style-type: none"> <li>Offers access to expert advice and support on caregiving</li> </ul>	<ul style="list-style-type: none"> <li>Carer support nurse conducts a wellness check-in with caregivers to enquire on how they are feeling and discuss if they have any concerns or caregiving concerns</li> <li>Depending on caregivers' needs and concerns raised, caregiver support nurse can provide (1) Expert advice on management of their care recipient or escalate to relevant care providers, (2) Help caregivers navigate through the complex healthcare and social service systems, (3) Connect caregivers to community partners and support services, (4) Emotional support and encouragement for their caregiving role</li> </ul>	Carer support nurse
3b	Carer training programmes	<ul style="list-style-type: none"> <li>Provide education, support, and skills training to better equip caregivers to manage their responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>Prior to the programme, caregiver support nurse ensures that caregivers are able to operate the video conferencing platform and did not encounter any technical difficulties with their webcam and microphone. Pre-programme survey forms are also sent out to the caregivers</li> <li>Carers attend group-based session, conducted by caregiver support nurses and programme facilitators (Registered nurses and other healthcare professionals)</li> <li>Programmes focused on teaching of knowledge and skills with social learning to help caregivers learn of other strategies used by peers</li> <li>For the CARERS programme, caregivers can also learn practical skills to improve communication and better manage the behavioural and psychological symptoms of dementia (e.g. agitation, aggression) of their loved ones. The CARERS programme is conducted by programme facilitators who have been trained to simulate specific challenging situations encountered by caregivers at home</li> <li>Carers given materials covered during session and follow-up resources. Carers also directed to complete the post-programme survey form a week after attending the programme</li> </ul>	Carer support nurse Facilitators
4	Community partners	<ul style="list-style-type: none"> <li>Connect stressed caregiver to network of community partners to help them thrive at home</li> </ul>	<ul style="list-style-type: none"> <li>Carer support nurse identifies and introduces relevant programmes and/or services in the community that are appropriate for the caregiver. Carer support nurse obtains consent from caregiver to be connected to the service provider</li> <li>Carer support nurse alerts the community partner on the caregivers' needs and caregiving context and completes any relevant referral forms</li> <li>Carer support nurse handover caregiver to community partner for prolonged follow-up</li> </ul>	Carer support nurse Community partner
5	Carer support network	<ul style="list-style-type: none"> <li>Connect caregiver to network of peer caregivers and informal support network, to learn from each other's experience</li> </ul>	<ul style="list-style-type: none"> <li>Carer support nurse identifies suitable support network for caregiver based on their needs and interests</li> <li>Carer support nurse introduces network to caregiver</li> <li>Support network buddies together with caregiver to help them adjust and adapt to roles and responsibilities</li> </ul>	Carer support nurse Peer caregivers

the training reported that they were able to apply its lessons to their day-to-day management of the PwD.

While the above-mentioned services and support are delivered by the Carer Matters project team in the hospital, it is important to ensure caregivers of PwD continue receiving support and knowledge reinforcement on positive coping techniques and access to information on available community-based assistance. Hence, the 'last lap' of Carer Matters is connecting caregivers to our network of community partners, non-government organizations and social service providers that deliver assistance to both the caregiver and the PwD living in their region (component 4). In addition, through the range of activities and engagement with caregivers and community partners, we are establishing a support network of community partners and/or buddy caregivers. Together, these two interventions help the caregiver and the PwD better adjust to life at home, surrounded by a community of carers (component 5). The effectiveness of grassroots-level activation and improvement of psychological wellbeing of older adults was demonstrated in family/group counselling interventions in the United States, with participants reporting lower depression and better management of their reactions to the PwD's behavioural symptoms (Sperling et al., 2020). Learning from the success of such initiatives, Carer Matters aims to incorporate the tertiary hospital and its networks into the caregiving ecosystem, establishing community networks for ground-up connection and engagement between hospital and community providers to caregivers.

As seen in components (1)–(5), Carer Matters offers a holistic end-to-end platform of resources, training, and support to aid and equip caregivers of PwD, helping them thrive and sustaining their caregiving journey. Through Carer Matters, we seek to improve the mental, emotional, and physical health of caregivers of PwD, decrease caregiving stress, and improve caregiving coping ability.

However, as the first of its kind to date in the local setting, it is important to examine its feasibility in Singapore. This necessitates a better understanding of the specific barriers and facilitators to the delivery of Carer Matters, and the possible underlying mechanisms in Carer Matters that contribute towards observed outcomes. These findings would allow further fine-tuning and enhancement of Carer Matters to ensure it can benefit the many caregivers of PwD in Singapore.

## 3 | THE STUDY

### 3.1 | Aims

The aims of our study are as follows:

1. To explore the barriers and facilitators of acceptance and implementation of Carer Matters.
2. To conceptualize a Theory of Change (ToC) model that reflects Carer Matters' multi-pronged interventions and projected impact on caregivers, their care recipients, and the healthcare system.

### 3.2 | Design

A multimethod study design will be used to collect, analyse, and interpret quantitative and qualitative descriptive data. This is a feasibility study to examine if the Carer Matters approach can be scaled up across the organization.

Our overall evaluation of Carer Matters is built off the ToC conceptual framework. This is a pragmatic framework that is focused on mapping out how and why a programme is expected to work and achieve its desired goals in the real world as opposed to in a controlled experimental setting and has been used widely around the world (De Silva et al., 2014). It does this by first identifying the desired impact and long-term outcomes then looks backwards to identify all the preconditions (i.e., short- and medium-term outcomes) that must be in place for the long-term outcomes to be achieved. The interventions needed to move from one precondition to the next for achieving the long-term outcomes are also identified. This approach allows us to better clarify the aims, objectives and outcomes of Carer Matters and the mechanisms that underpin the programme's ability to affect the caregiving ecosystem (De Silva et al., 2014).

Our initial ToC map is presented in Figure 2. This map describes the causal pathways of how Carer Matters achieves the long-term outcome in caregivers of "improved capacity for sustained caregiving of the PwD". This was built off a discussion with a range of stakeholders—caregivers of PwD, hospital leaders, community partners, caregiver support nurses, and ward nurses—which led to a consensus on the process and outcome indicators for each precondition in the pathway, and the key assumptions that set out the conditions needed in the casual pathway to achieve the impact.

### 3.3 | Study setting

Our study will involve six inpatient wards of a 1700-bedded tertiary care hospital which are piloting Carer Matters. These wards comprise of four acute wards and two sub-acute wards. They are selected as they admit a comparatively greater number of patients with dementia than other wards in the hospital. The study will be conducted over 12 months.

### 3.4 | Data collection

Our strategy for data collection and analysis is built off the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework. This would allow us to examine if the essential Carer Matters elements (1) affects our target population of caregivers of PwD—*Reach*, (2) brings about the desired effects in caregiver participants—*Effectiveness*, (3) is taken up well by our target population, healthcare and community service providers—*Adoption*, (4) is adhered according to our proposed implementation plan—*Implementation* and (5) is suitable for scaling and sustainment without excessive modification from the originally planned framework

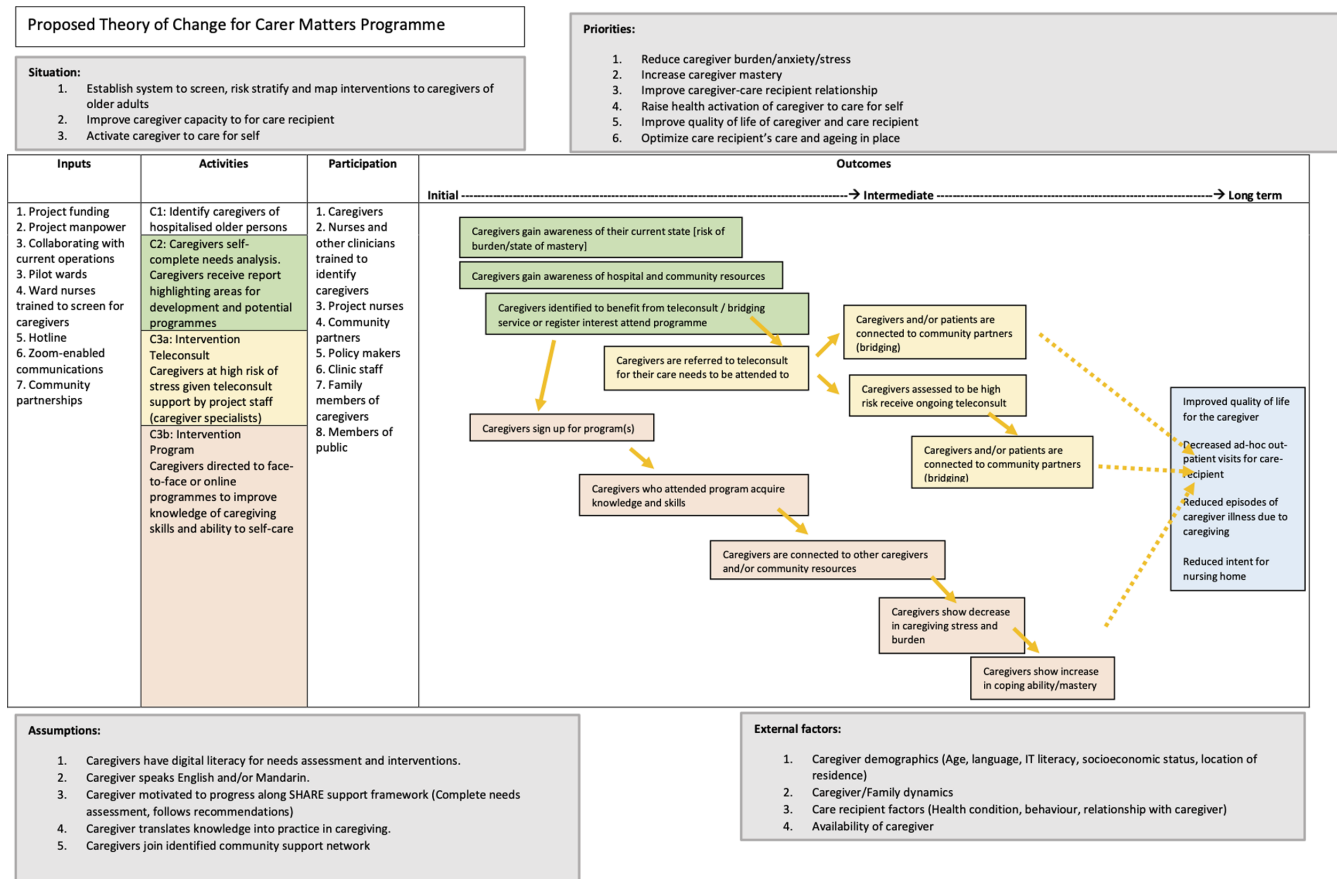


FIGURE 2 Proposed theory of change map for Carer Matters programme

of Carer Matters—Maintenance (Gaglio et al., 2013). Through the RE-AIM framework, we can obtain the findings needed to improve the sustainable take-up and delivery of Carer Matters effectively. This approach has also shown promise in the evaluation of community-based support programmes for caregivers (Samia et al., 2014).

Data collection will primarily consist of qualitative interviews, with some quantitative methods as detailed below.

### 3.5 | Qualitative component

Our qualitative component consists of themes identified through individual semi-structured interviews with key stakeholders of Carer Matters.

#### 3.5.1 | Participants

The key stakeholders comprise of (1) family caregivers of PwD ( $n = 25-30$ ), (2) ward nurses ( $n = 8-10$ ), (3) caregiver support nurses ( $n = 2-3$ ), (4) intervention programmes facilitators and standardized patients ( $n = 3$ ), (5) community partners and hospital leaders ( $n = 4$ ), and (6) other clinicians—medical social workers, physiotherapists, occupational therapists, and doctors ( $n = 4-5$ ).

#### 3.5.2 | Eligibility criteria

Our inclusion criteria for all participants in our qualitative data collection are as follows: (1) above 21 years of age and (2) able to converse in English language. We have additional inclusion criteria for participants from each of the target groups to be interviewed.

For family caregivers, we would recruit individuals who are the main family caregiver of the PwD receiving home-based care.

For ward nurses, we would recruit individuals who are (1) working as a nurse at one of the inpatient wards piloting Carer Matters and (2) referred family caregivers to complete the brief screening tool.

For caregiver support nurses, other clinicians, and programme facilitators, we would recruit individuals who are involved in either providing direct or indirect patient care to a PwD and their caregiver through Carer Matters.

For hospital management and leaders, we would recruit individuals who are key decision-makers or in leadership positions in the hospital.

For representatives of social service agencies, we would recruit individuals who are (1) working in institutions where there are ongoing or potential future partnerships with TTSH to provide care services for PwD and their caregivers and (2) key decision-makers or in leadership positions in their institutions.

We will exclude any potential participant who refuses to have their interviews recorded.

### 3.5.3 | Recruitment

Family caregivers of PwD admitted into the pilot wards who fit our inclusion criteria will be highlighted to the study team by attending clinical staff in the ward. The study team will approach these caregivers to further explain the study details and assess their eligibility for participation. Individuals who agree to participate will be met by the study team to provide written consent.

Ward nurses and other clinicians who are eligible will receive a recruitment letter distributed by their department heads. The study team will also join their department meetings and roll calls to share the study. The study team will approach individuals who express interest to further explain the study details and assess their eligibility for participation. Individuals who agree to participate will be met by the study team to provide written consent.

Hospital management staff and representatives of social service agencies will receive a letter of invitation via email, with the study team contact details attached for reference. This would allow interested individuals to directly contact the study team. The team will then further explain the study details and assess their eligibility for participation. Individuals who agree to participate will be met by the study team to provide written consent.

### 3.5.4 | Procedures

We will conduct one-time individual interviews using semi-structured interview guides with key stakeholders of the Carer Matters programme. The interviews will focus on (1) their views of Carer Matters, (2) facilitators and barriers to acceptability and implementation of Carer Matters, (3) issues associated with sustaining Carer Matters, and (4) processes that need to be fine-tuned for the scaling and sustaining of Carer Matters.

All interviews will be audio-recorded and conducted on a voluntary basis. One researcher who is well-trained in qualitative research methods and independent of the development and execution of Carer Matters will conduct all the interviews. In addition, emotions, pauses, non-verbal language, and significant observations of the participants which could not be captured by audio recording will be recorded as field notes.

### 3.5.5 | Data analysis

Audiotape recordings for each interview will be transcribed verbatim and double-checked to ensure the accuracy of transcription. Transcripts will be sorted, coded, and categorized accordingly to

facilitate thematic analysis, aligning codes, subthemes, and themes against the Reach, Effectiveness, Adoption, Implementation and Maintenance of Carer Matters. Our application of the ToC model would help ensure completeness of our inquiry and understanding of the relevant factors that enable or hinder the effective rollout and engagement of Carer Matters by caregivers and other stakeholders in the hospital and community ecosystem (Holtrop et al., 2018).

## 3.6 | Quantitative component

Our quantitative data are based on surveys and programme data collected from all family caregivers who participate in Carer Matters.

### 3.6.1 | Participants

Participants will consist of all caregivers of PwD whose care recipient is admitted into the pilot wards and agree to participate in Carer Matters.

### 3.6.2 | Eligibility criteria

Our eligibility criteria for participants to enter Carer Matters—whose information is captured in our quantitative data collection—are as follows: Family caregivers of a PwD who are (1) above 21 years of age, (2) the main family caregiver of the PwD receiving home-based care, and (3) able to read and converse in English.

We will exclude any caregiver whose care recipient is planned for discharge to a long-term care facility, such as a nursing home.

### 3.6.3 | Recruitment

Caregivers of PwD who are eligible for Carer Matters will be invited by ward staff to perform the brief needs assessment and hence receive the appropriate Carer Matters interventions. Verbal consent is obtained before they receive the interventions, and their information will be used to help evaluate the programme.

### 3.6.4 | Procedures

We will also be collecting indicators related to the demand and acceptability of the Carer Matters programme. The following data will be collected: (1) Carer Matters programme log to store information related to the demand for the Carer Matters such as number of family caregivers screened, number of family caregivers assessed for needs, number of family caregivers provided with assistance through in-house services or referred to our partnered community-based agencies, etc. The log will also document information related to the work or implementation processes such as length of time to

perform the screening and needs assessment, training hours for ward nurses and Carer facilitators, and etc; (2) Carer Matters programme satisfaction survey to ask family caregivers about their satisfaction with the Carer Matters programme; (3) Intervention programme log to store information related to the demand for the caregiver intervention programme such as the demographics of participants for each intervention programme, attendance and drop-out rate of the programme, and etc; (4) Programme surveys that capture appropriate psychological measures such as caregiver burden as measured using a modified version of the Zarit Burden Inventory, caregiver anxiety and depression as measured using the Hospital Anxiety and Depression scale, caregiver competence as measured using the Caregiver Competence scale and caregiver mastery as measured using the Personal Mastery scale (Pearlin et al., 1990; Pearlin & Schooler, 1978; Zarit et al., 1980; Zigmond & Snaith, 1983) and (5) Programme satisfaction surveys.

### 3.6.5 | Data analysis

Descriptive statistics such as mean, standard deviation, median and interquartile range will be used to describe caregiver-specific outcomes captured. Paired-*t*-tests will be applied to examine the effect of Carer Matters interventions on caregivers' reported depression, anxiety, and mastery scores before and after Carer Matters interventions. Data analysis will be conducted using Jamovi version 1.6.23 (The Jamovi Project, 2021). Statistical significance will be set as  $p < .05$ .

### 3.7 | Refinement of ToC model

Both qualitative and quantitative data will be triangulated to generate an updated ToC model explaining how Carer Matters improves caregiver capacity for sustained caregiving of the PwD. This final ToC model will reflect the processes and mechanisms of Carer Matters that contribute towards the short, medium, and long-term outcomes we intended and can serve as a guide for future researchers and practitioners.

### 3.8 | Ethical considerations

The purpose of this study will be explained to prospective eligible study participants, and the expected level of involvement. Potential caregiver participants will be reminded by the research assistant that their participation in the study is voluntary and that it would not affect their ability to engage in the interventions in the Carer Matters programme.

Written consent will be sought from individuals who agree to participate in the semi-structured interviews. Each participant will retain a signed copy of the consent form containing the Principal Investigator's contact details if they have further queries. A token

cash voucher will be provided to participants after their completion of the interview as reimbursement for their participation in the study.

As the quantitative data collected in this study consists of the programme logs and data of all Carer Matters participants, verbal consent is sought from all caregivers identified to receive Carer Matters interventions, with a participant information sheet that as part of the evaluation and improvement of the service, the information they furnish will be anonymized and aggregated for analysis.

## 3.9 | Validity and rigour

To ensure rigour in our study, we will apply the principles specific to both the qualitative and quantitative study designs.

### 3.9.1 | Qualitative validity

The credibility of our qualitative analysis will be ensured by complying with the recommended principles for qualitative analysis when applying the RE-AIM framework (Gaglio et al., 2013; Holtrop et al., 2018). Two researchers will code all transcripts independently, ensuring consistency in the coded data across the multiple groups of participants. This will be further supported through field notes, audit trails and regular team meetings to enhance the trustworthiness of the codes identified and themes developed.

### 3.9.2 | Quantitative validity

The outcome measures used in this study—the Caregiver Competency Scale, the Caregiver Mastery Scale, the Hospital Anxiety and Depression Scale and the Zarit Burden Interview—have been validated for use in caregivers of PwD in our earlier research and have been applied in studies of family caregivers (Chan et al., 2018; Chan, Lim, et al., 2019; Liang et al., 2016). In addition, these measures are both easy to understand and capable of being self-administered by caregivers, making them appropriate tools for use.

## 4 | DISCUSSION

Caregiving is a journey that often requires caregivers to adjust and adapt to the needs of their loved ones until their passing or institutionalization (Chan, Phang, et al., 2019; Thai et al., 2016; Thomas et al., 2017). Recognizing this, caregivers would be better supported through a long-term support structure. To our knowledge, Carer Matters is the first holistic hospital-to-home framework of support-oriented specifically around the needs of caregivers of PwD in Singapore, addressing their physical, emotional, and psychological needs. Through this, caregivers would be better supported and



equipped with the skillsets and capacity to continue caring for their loved ones.

Hence, our study is vital in examining its feasibility, providing insights on this holistic hospital-to-home approach. Carer Matters may benefit family caregivers, patients, as well as the healthcare system, with family caregivers and their loved ones, as the main beneficiaries of the programme. This approach further develops the role of nursing, growing from focusing on the holistic care of a single patient towards encouraging their caregiver as well, better anticipating their needs and opportunities to support them so patients and their caregivers can both thrive at home together.

These findings will be useful in guiding policymakers on the feasibility and sustainability of running such an extensive framework of support for caregivers of PwD and in a wider scope, caregivers of older persons.

These findings will be invaluable in guiding nursing practice, models of care and policy, shifting the focus from the patient alone to include their caregiver as well.

The dissemination of findings will include publications and presentations at international geriatric nursing conferences. In addition, we will share our findings with clinicians, policymakers, and members of the public through the media and our organization's networks to care organizations in and without Singapore. This ensures that the lessons and insights can guide the support of caregivers both in Singapore and beyond.

## 5 | LIMITATIONS

While we will be examining the effectiveness of Carer Matters through the experiences and reported outcomes of caregivers who receive the interventions, we will not establish a control group to compare the 'effect' of Carer Matters against due to logistic and ethical concerns.

Another limitation is that the study will be conducted in the midst of the ongoing COVID-19 situation. This may have some influence on the caregiver's stress and may influence our findings. In addition, it might limit our ability to recruit a large number of caregivers to participate in our interviews due to physical visitation limitations imposed as part of COVID-19 safe management measures.

While our quantitative data might report changes in reported burden, anxiety and depression, we hope to use our qualitative data to better understand how caregivers' perceived burden and negative emotions changed.

## 6 | CONCLUSION

Caregivers of PwD often face many sources of stress, beyond those arising directly from the management of their loved one alone. Carer Matters is a holistic programme to help better equip and empower caregivers to better manage the care of their loved

ones and continue caregiving in the long run. Our feasibility assessment of Carer Matters would allow us to better examine how such a hospital-to-home identification, education, engagement, and support framework can be delivered for caregivers of PwD in Singapore and beyond.

### TRIAL REGISTRATION DETAILS

Trial registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Reference number: NCT05205135. Title: Feasibility Study of Project Carer Matters for Family Caregivers of People With Dementia Receiving Home-based Caregiving.

### ETHICAL REVIEW

The study protocol was reviewed and approved by the National Healthcare Group Domain Specific Review Board (DSRB Ref: 2020/00087). This study has also been externally peer-reviewed and awarded funding through the Geriatric Education and Research Institute (GERI) Intramural Project Grant (GERI Ref: GERI1626) on 15 May 2020 for this study (£103,659), with approval for its conduct from 01 December 20 to 1 June 2022. This study has been registered on [ClinicalTrials.gov](http://ClinicalTrials.gov), reference NCT05205135.

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### CONFLICT OF INTEREST

The authors declare no conflicts of interest, financial or otherwise.

### AUTHOR CONTRIBUTIONS

Ee-Yuee Chan conceptualized the Carer Matters programme and its services. Ee-Yuee Chan and George Frederick Glass Jr designed the feasibility study and the multimethod approach of evaluation. Ee-Yuee Chan and George Frederick Glass Jr drafted the final manuscript. All authors gave final approval of the manuscript version for publication.

### PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15210>.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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