Enquiry Question: **Evaluation of the social support to dementia family caregivers in Hong Kong**

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<td>1. Written reports should not exceed 4,500 words. The reading time for non-written reports should not exceed 22 minutes and the short written texts accompanying non-written reports should not exceed 1,100 words. The word count for written reports and the short written texts does not include the covering page, the table of contents, titles, graphs, tables, captions and headings of photos, punctuation marks, footnotes, endnotes, references, bibliography and appendices.</td>
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<td>2. Candidates are responsible for counting the number of words in their reports and the short written texts and indicating it accurately on this covering page.</td>
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<td>3. If the Independent Enquiry Study Report of a student is selected for review by the School-Based Assessment System, the school should ensure that the student’s name, class/group and class number have been deleted from the report before submitting it to the Hong Kong Examinations and Assessment Authority. Schools should also ensure that the identities of both the schools and students are not disclosed in the reports. For non-written reports, the identities of the students and schools, including the appearance of the students, should be deleted.</td>
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A. Problem Definition

In line with global trends, the average age of the population in Hong Kong has been increasing rapidly. It is projected that in 2036, there will be more than 2.3 million people aged 65 and above.\(^1\) Since the prevalence of dementia increases exponentially with age, the number of persons suffering from dementia rises significantly with the changing demographics and this has been described as a ‘tidal wave on the horizon’\(^2\). About 1 in every 10 over-70s has dementia and by the age of 85 about 1 in 3 will have it.\(^3\) The predicted number of patients may reach over 332000 by the year of 2039\(^4\). There is definitely a pressing need for the society to deal with this problem.

It has long been recognized that the impact of dementia goes far beyond the patients, but also their family caregivers. Alzheimer’s and other types of dementia now constitute the fourth leading cause of disease burdens in high-income countries\(^5\), including Hong Kong.

As our population continues to age, family caregivers are faced with increasing demands. Numerous studies have highlighted its deleterious psychological, physiological and financial effects on family caregivers.\(^6\) If these problems are remained ignored, more family tragedies like a 56-year-old overstressed man committed suicide after killing his wife who had suffered from dementia for years.\(^7\) Therefore, appropriate social support to caregivers are undoubtedly essential in alleviating caring stress and improving quality of life of caregivers. Understanding their experience can also help service providers design effective interventions to alleviate their burden.

Support for caregivers is the foundation for effective dementia care, because most caregiving of dementia patients is provided by their family members. In Hong Kong, however, the situations of caregivers for the elderly with dementia have not been adequately studied. Therefore, the aim of this enquiry is to explore the burdens faced by them and conduct an evaluation on the existing social supportive measures offered and suggest appropriate interventional strategies for further service enhancement.

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2 Sabat SR (2009); Dementia in developing countries: a tidal wave on the horizon


4 Yu R, et al. (2012); *International Journal of Alzheimer’s Disease*


7 Hong Kong couple found dead in suspected murder-suicide (15 February 2017); *South China Morning Post*
Focus Questions

1. What burdens do the family caregivers face when taking care of the patients?
2. What are the existing measures or assistance offered by the government and NGOs now to support the family caregivers of patients with dementia?
3. How do the family caregivers and other stakeholders like social service professionals think about the above existing supportive measures offered?
4. How can the government or NGOs do for further service enhancement to alleviate the family caregivers’ burdens?

Methodology

(a) First-hand data

Two in-person interviews will be conducted with a dementia family caregiver and a social worker providing elderly service respectively.

For the former one, Ms. Li would be interviewed. She has been an experienced dementia family caregiver, who has seven years of caregiving experience for her demented father. More detailed information of dementia family caregivers’ real-life obstacles and their opinions on the existing social support.

The latter one would be conducted with Ms. Esther Tsang. Being a social worker specializing in elderly service for more than 10 years, Ms. Tsang’s close contact with dementia family caregivers can certainly facilitate an in-depth evaluation of existing social supportive measures with accurate and comprehensive information gathered from a social service professional.

(b) Second-hand data

Facts and statistics would be collected from official researches and articles from medical journals. The quality and quantity of existing supportive measures provided by government and non-governmental organizations (NGOs) will also be evaluated in terms of adequacy, accessibility and usefulness based on information gathered from websites of some local and overseas supporting organizations, news reports, etc.
B. Relevant Concepts and Knowledge/ Facts/ Data

**Dementia**

Dementia is a brain disorder. Being among the top ten causes of death in Hong Kong, brain cells of dementia patients die quickly when they grow older and their brains will shrink, causing severe deterioration of brain functions. They may not only become forgetful, but also have problems with understanding, language and judgment. Alzheimer's disease is the most common type and severe patients may be unable to take care of themselves and be totally dependent and even bedridden. Therefore, the severity of dementia implies that substantial amount of family caregiving is needed and thus an evaluation on social support to family caregivers is definitely worthwhile to be conducted.

**Life expectancy and Ageing population in Hong Kong**

Life expectancy at birth in Hong Kong has been on the rise for decades, from 72.3 years for men and 78.5 years for women in 1981 to 81.4 years and 87.3 years in 2015 respectively, ranking the first in the world. It is well known that dementia becomes more prevalent with increasing age and especially for females (refer to Fig. 1), hence, the number of dementia patients is expected to have a significant **threefold increase** from 2009 to 2039, with substantially rising burden on long-term health and social care.

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8 Hospital Authority Smart Patient Website; Dementia; Retrieved from http://www21.ha.org.hk/smartpatient/en/chronicdiseases_zone/details.html?id=174#8
10 Chiu HF (1998); Prevalence of dementia in Chinese elderly in Hong Kong. Neurology; 1002-1009
Family caregivers would need to be an integral part of care by accompanying the patients for daily activities and medical treatment round the clock. Thus, quality and sufficient social support should be provided to them to ease care stress. Therefore, given the potential growth in number of dementia family caregivers, existing social support should be evaluated to assess whether Hong Kong is well-prepared for the challenges caused by ageing population.

**Burdens faced by dementia family caregivers**

(a) **Psychological stress**

The most distinguishing feature of the caregivers for dementia patients is the proportionately large numbers who experience stress and this constitute the major burden faced by them. Constant attention and the lack of meaningful feedback form patients may result in carer stress. Some may feel strained and depressed due to long hours of caregiving without sufficient rest and relaxation. As a result, a wide range of negative emotional responses can be identified, for instance, depression, anxiety, guilt, blame, fear, and embarrassment.
(b) Physiological problems

Deterioration in health can also be observed from dementia family caregivers due to their large involvement in patient care. Some may suffer from sleeping disruptions or even hallucinations. Besides, arthritis, high blood pressure or other chest problems are also some common health problems found in family caregivers. Given their health issues, they may feel their inability to take care of the patients much longer.13

(c) Interrupted daily routine

Family caregiving to dementia patients requires a lot of time commitment in which caregivers may find it demanding to help their family members with their activities of daily living. Provision of care 24 hours a day all year round constituted one of the major sources of burden. Some may even be unable to have regular work because they have to attend to the care recipients almost round the clock.14

(d) Insufficient information

Researches have pointed out that dementia family caregivers face difficulty in seeking information concerning the disease. When family caregivers encounter challenging behaviours exhibited by their loved ones with dementia, they do not know how to deal with them, nor whom to approach for help. Caregivers’ lack of knowledge about services available in the community may lead to low levels of utilization of the supportive measures.15

The above are the major burdens encountered by dementia family caregivers and this report will further evaluate on whether the existing social support can address on the mentioned challenges in different aspects.

Family caregivers are integral to the quality of life of dementia patients. If caregivers experiencing significant burdens for long but no interventions are given, there would be a detrimental effect on their physical and mental well-being, which hinder them from continuing the caregiving and opt for institutionalization. Hence, more patients have to separate from their beloved ones whom they can rely on most comfortably. This would not be beneficial to their recovery process.

13 Hazlett C. (1994); Highlights of the Canadian-Alberta Study of Dementia: The Caregiver’s Burden; Hong Kong Journal of Gerontology Vol 8 No 1; 19-21
14 W.C. Chan (April 2007); Determinants of Burden Among Informal Caregivers of Dementia Persons in Hong Kong; Asian Journal of Gerontology & Geriatrics Vol 2 No 1; 33-34
Existing social support

It is mainly divided into two categories in which the service providers are the government and NGOs respectively.

**Government**

<table>
<thead>
<tr>
<th>Hospital/Department</th>
<th>Nature</th>
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<tbody>
<tr>
<td>Caritas Medical Centre</td>
<td>Memory Clinic/Department of Old Age Psychiatry:</td>
</tr>
<tr>
<td>Castle Peak Hospital</td>
<td>· Providing <strong>memory and cognitive assessment</strong> for people who are suspected of suffering from dementia, followed by medical treatment and rehabilitation services</td>
</tr>
<tr>
<td>Haven of Hope Hospital</td>
<td>· Providing <strong>community outreach services</strong> for elderly patients, e.g. psychogeriatric outreach services, community geriatric assessment team outreach services and community nursing services</td>
</tr>
<tr>
<td>Kwai Chung Hospital</td>
<td></td>
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<tr>
<td>Kwong Wah Hospital</td>
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<tr>
<td>Queen Mary Hospital</td>
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<td>Ruttonjee Hospital</td>
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<tr>
<td>United Christian Hospital</td>
<td></td>
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<tr>
<td>Social Welfare Department</td>
<td>Providing <strong>family and casework services, counselling and referral services</strong> for dementia family caregivers by professional social workers</td>
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**Non-governmental organizations (NGOs)**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Nature</th>
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<tbody>
<tr>
<td>Jockey Club Centre for Positive Ageing</td>
<td>Providing <strong>day care and residential service, home-based training</strong> for patients and <strong>training courses or health seminars</strong> for family caregivers</td>
</tr>
<tr>
<td>Jockey Club Cadenza Hub</td>
<td>Day Care Centre providing one-stop services, e.g. <strong>cognitive training, self-care training, rehabilitation training and psychosocial activities</strong></td>
</tr>
<tr>
<td>The Charles K. Kao Foundation for Alzheimer's Disease Limited</td>
<td>Providing <strong>funding</strong> for the “Reaching out Dementia Caregiver Support Project” - provision of <strong>free-of-charge comprehensive health assessments, multi-component psychosocial and behavioural</strong></td>
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</tbody>
</table>
(Please note this list is not exhaustive and only includes some of the major social support)

The above tables present examples of social support provided by the government and NGOs.

Assessment criteria

All of the above measures will be evaluated in this report in terms of their adequacy, accessibility, and usefulness in alleviating dementia family caregiver’s burdens.

Rationales behind the social support to dementia family caregivers

Family caregivers of dementia patients are often a “forgotten” group. Their well-being is often overlooked and considered secondary. As a result, they may face difficulties in arranging daily routine and seeking related information. Negative impacts to their psychological and physiological health can also be observed. However, family caregivers are the ones whom dementia patients spend most of their time with. The family caregivers’ satisfactory condition can effectively facilitate the caregiving and recovery process of the patients. It is hoped that caregivers’ stress can be relieved through assessments, counselling, and proper caregiver training. Thus, the well-being and quality of life of dementia caregivers can be enhanced. In the enquiry, the existing social support to dementia family caregivers will be evaluated to see whether the mentioned rationales are achieved. If these rationales are not met, there is certainly room for improvement on existing policies.

C. In-depth Explanation of the Issue

Caregiver burden of highest significance

**Psychological stress** is the most typical burden encountered by dementia family caregivers in comparison to other burdens such as physiological problems, insufficient information or knowledge about dementia and disturbance to daily routine.

In the interview conducted with *Ms. Esther Tsang*, a social worker providing elderly service (*For interview details, refer to Appendix 1*), she said that the most commonly observed burden is the huge psychological stress due to demanding care. Most of this stress resulted from the constant attention required and the lack of meaningful feedback from the patient to the caregiver. Caregivers may get annoyed when they have to repeatedly answer the same question for even over 100 times a day. After every day long-hour care, they may feel strained easily due to insufficient rest. When overstressed, **psychosomatic disorders**\(^{18}\) may even occur.

From the perspective of a caregiver of a demented person, *Ms. Li* expressed her worries upon her father’s diagnosis of having dementia 7 years ago. (*For interview details, refer to Appendix 2*) At first, her father felt anxious easily when he realized that he started to forget things. Due to low sense of security, he always sought for attachment to his wife who was his closest person. “*At first, my mother can’t accept my father’s rapid deterioration in cognitive level. Also, she felt overwhelmed and strained due to long-hour care. She couldn’t handle and developed depression which affected her psychological and physical health a lot.*” This showed that some family caregivers may not be psychologically ready for the drastic change to their own social life due to their caregiver roles. If supportive counselling is not given properly, **deleterious effect on psychological health and quality of life can be resulted.**

Besides, WC Chan (2010) stated that 70% of the participants report psychological distress being the most significant caregiver burden.\(^{19}\) Respondents once recalled their poignant feelings as “*I find it very painful to look after my husband. The pain is always there.*” and “*I am so ambivalent and distressed. I think it’s too cruel to send her to a nursing home. I feel guilty towards her and blame myself for having such thoughts.*

\(^{18}\) RL Kradin (2011); Psychosomatic disorders: the canalization of mind into matter; *Journal of Analytical Psychology*; 37-55

\(^{19}\) WC Chan (2010); Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study; *East Asian Arch Psychiatry*; 163-168; [http://easap.asia/journal_file/1004_V20N4_p163.pdf](http://easap.asia/journal_file/1004_V20N4_p163.pdf)
However, I find it too exhausting to look after alone. Caregiving is really depressing.”

These agonizing remarks reflected that the demanding round-the-clock care for demented persons can cause significant psychological distress to solo family caregivers. Sending the demented elder to long-term residential elderly home may not be an option for some caregivers as they find it guilty for abandoning their beloved ones in an unfamiliar place. The sense of guilt may also increase the psychological stress.

Comments on existing social support to caregivers

In Hong Kong, the major social support to caregivers can be categorized into three main types.

1) Day care service
2) Residential care service
3) Caregiver skills training

In general, WC Chan (2010) pointed out that caregivers’ perceptions about the usefulness of social services differs across the spectrum of dementia. Caregivers of persons with milder dementia found day care facilities more useful while those of late-stage dementia prefers residential care services.

1. Day care service

Caregivers of persons with mild to moderate dementia can consider adopting day care service, which can ease caregivers’ stress by allowing caregivers to take rest in times of need. T Kwok (2013) pointed out that day care services for people with dementia reduce caregiver stress significantly, through restructuring caregiving time and alleviating burdens.

However, the provision of Specific Dementia Day Care Centre in Hong Kong cannot meet the high demand. Although there are more than 200 subsidized elderly day care centres, only about 20 cater specifically to dementia patients, coping with only about 10% of the over 110,000 of people with dementia.

Moreover, patients with severe dementia can also develop sundown syndrome, in which they would have behavioural problems at night. Nina

WC Chan (2010); Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study; East Asian Arch Psychiatry; 163-168; http://easap.asia/journal_file/1004_V20N4_p163.pdf
T Kwok (2013); Effectiveness of day care services for dementia patients and their caregivers; Asian Journal of Gerontology and Geriatrics; Vol. 8; No. 1; 9-15; http://ajgg.org/AJGG/V8N1/2011-105-OA.pdf
Khachiyants (2011) found that the prevalence of it has been increasing recently\(^{22}\). However, in Hong Kong, there is just one specific centre called Haven of Hope Memory Care for Elderly\(^{23}\), which ameliorate the stress of caregivers of these patients who aged over 70. This echoes with the fact that existing dementia-specific social support is significantly inadequate.

Ms. Li mentioned in the interview that before sending her father to stay in residential care centre, she would like to find day care service for her father for receiving some cognitive training. However, neither she nor other family members were aware that there were actually some specific dementia day care centre in society. Therefore, she chose a general elderly centre which only provide some social activities and physical rehabilitation exercise designed for general elders but not especially for dementia patients. From this, it showed that the specific dementia day centres are not easily accessible enough for family caregivers.

Due to the limited adequacy and accessibility to these specific dementia day centres, some caregivers can only opt for service in general elderly centres, which provides basic care service like rehabilitation exercise and meals. However, the effectiveness of these general day care centres is in doubt. Ms. Esther Tsang noted that Dementia Day Care Centres, ideally, need staff to patient ratio of about 1: 6-8 patients, given that dementia patients have short attention spans, and are easily agitated and frustrated. The staff may not be aware of the demented elder leaving the centre alone, resulting in getting lost. Thus, specialized care should be designed according to the patient’s condition. However, the staff to elder ratio in general elderly centres are normally very high of about 1: 12 in which individual demented person’s needs cannot be addressed. Therefore, mixed usage of elderly centres for all will not work for obvious reasons.

In recent years, there are some NGO operated Dementia Centres set up, such as Jockey Club Centre for Positive Ageing. However, findings have pointed out that they are mostly run at a loss and are short staffed.\(^{24}\) Moreover, T Kwok (2012) mentioned that most of the day care services for demented are not funded by subvention.\(^{25}\) The daily usage charge is around HK$400, in which many family

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22 Nina Khachiyants (2011); Sundown Syndrome in Persons with Dementia: An Update; Psychiatry Investigation; 275-287; [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3246134/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3246134/)


25 T Kwok (2012); Case management to improve quality of life of older people with early dementia and to reduce caregiver burden; Hong Kong Medical Journal; Vol 18; No 6; 4-6; [http://www.hkmj.org/system/files/hkm1206sp6p4.pdf](http://www.hkmj.org/system/files/hkm1206sp6p4.pdf)
caregivers especially those with lower income level cannot afford huge cost.

2. Residential care service

Due to the chronic and progressive nature of dementia, residential care services become a choice for caregivers as the patient may start to develop physical impairment in late stage.

The above graph showed that residential care service in Hong Kong is mainly dominated by private homes in which the residential fee can be very expensive. The basic monthly fee can vary widely from $4500 to $21000. As caregivers with lower income cannot afford the heavy financial cost, they can only opt for subsidized places from the government which only constitute less than 40% of the total service.

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26 Social Welfare Department; Provision of Residential Care Services for Elders; Retrieved from http://www.swd.gov.hk/doc/elderly/ERCS/3Overview%20item(a)english%2031-12-2016%20rev.pdf
<table>
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<th>Subsidized Residential Care Service for the elderly</th>
<th>Average waiting time (in months)</th>
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<tr>
<td>Care and attention places</td>
<td></td>
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<tr>
<td>Subvented homes and contract homes</td>
<td>37</td>
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<tr>
<td>Private homes participating in “Enhanced Bought Place Scheme”</td>
<td>11</td>
</tr>
<tr>
<td>Nursing home places</td>
<td>23</td>
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The above table showed there is a long waiting queue for a subsidized place for residential care service for elderly. The waiting time for place in subvented home can be as long as three years. There can be a rapid deterioration in the patient’s cognitive level in this long period of time. Solo family caregiver who cannot afford private care service may not be able to take care of the patient at home alone. Therefore, the adequacy and accessibility of affordable residential care services should be greatly improved in foreseeable future.

3. Caregiver skills training

Upon diagnosis of the disease, training on dementia-specific caregiving skills should be provided to family caregivers on regular basis, in order to better equip them with sufficient knowledge and skills about the disease.

However, though Kin Chi Dementia Care Support Service Centre under St. James’ Settlement Continuing Care, which is one of the major NGO providing dementia service in Hong Kong, has introduced a carer training programme, its low frequency of service will lower its effectiveness. The training sessions are only held for five times a year²⁹, lasting for 1.5 hour each time, which is apparently not sufficient and constant enough.

WC Chan (2010) reflected that regardless of the stage of illness, carers agreed that problem-oriented skills training programmes were very practical and should be

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²⁹ St. James’ Settlement Continuing Care; Kin Chi Dementia Care Support Service Centre; Website: https://cc.sjs.org.hk/?route=services-detail&sid=35&lang=3
expanded both in scope and frequency. This suggested there is a room for expansion in the amount and frequency of dementia-specific training course in Hong Kong.

Ms. Li’s response also echoes with the above. Neither her mother, the domestic worker taking care of her father daily nor she has received any dementia-specific caregiver skills training before. She said this is mainly due to the low accessibility and adequacy of the training courses. Her family didn’t even know about their existence due to lack of promotion. “The caregiving experience would certainly be easier and less demanding if we are equipped with adequate skills. At the early stage, we didn’t know the correct communication skills with dementia patient should be teaching or telling them the old things, instead, we just kept asking him questions which would cause anxiety in him as he didn’t know the answer.” It reflects the importance and the necessity of dementia-specific training for caregivers.

Ms. Esther Tsang added that some family caregivers may choose to attend classes held by elderly centres as an alternative to the limited dementia-specific courses. However, there would be a disparity between the both. The former one would only introduce some basic and general caregiver skills for an elder such as teaching exercise for physical rehabilitation. The latter one would focus more on the special communication skills and cognitive exercise. It indicates that dementia-specific trainings for caregivers are irreplaceable.

Moreover, report stated that, under the existing Community Care Service Voucher for the Elderly, subsidy is only offered for patient themselves. Cost for caregiver supportive service like training are not under subvention. Apparent loopholes in the pilot scheme are seen.

Although Ms. Esther Tsang commented the existing dementia caregiver training as insufficient, she explicitly praised the work done by “Charles K. Kao Foundation for Alzheimer’s Disease Limited” since its foundation in 2010. 'By providing funding in collaboration with care centres in community, it ensures the most comprehensive and also affordable free-of-charge training specially designed for dementia family caregivers.' Ms. Tsang’s remarks reminds us though there are a few successful support groups in society, existing training should be expanded in scope to meet the large demand of caregivers in the near future.

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3018 WC Chan; Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study; East Asian Arch Psychiatry; 2010; 163-168; http://easap.asia/journal_file/1004_V20N4_p163.pdf
D. Judgement and Justification

In Hong Kong, although the government has started to put more efforts on dementia care these years, the provision of existing social support has not yet caught up the uprising number of dementia patients in this ageing city.

Although there are some successful moves to better support dementia family caregivers in recent years like the “Reaching out Dementia Caregiver Support Project” carried out by Charles K. Kao Foundation for Alzheimer’s Disease Limited, more comprehensive caregiver-oriented social support should be introduced and made accessible to family caregivers, in preparation for the drastic increase to 332,000 dementia patients in 2039.

Evaluation on the measures’ adequacy, accessibility, and usefulness showed that the effectiveness of existing social support to dementia family caregivers still remains low to cater their psychological and practical needs.

1. Adequacy of social support

The adequacy of existing support is low which cannot meet the high demand of family caregivers.

1.1 Shortage of dementia-specific support

The major reason contributing to caregivers’ huge psychological stress is the constant attention required for the patient. To alleviate this problem, provision of dementia-specific day care centres can certainly allow caregivers to enjoy some free time without worrying about the safety of their beloved ones.

However, although there are more than 200 subsidized day-care centres for the elderly in Hong Kong, only about 20 cater specifically to dementia patients, who require more physical and mental care like cognitive training. Given that there are around 110000 dementia patients in present, only around 10% of patients are able to obtain a place in these centres as mentioned in previous part. The remaining 99000 patients’ caregivers are not provided with adequate support, facing the challenges and obstacles alone.
For more severe cases, those with sundown syndrome—those who have behavioural issues at night, and may yell and even attack family members—there is only one specific centre called Haven of Hope Memory Care for Elderly, which allows caregivers to catch up on much-needed sleep. However, the centre cater only to those over 70, therefore, for those diagnosed with dementia in their 60s or even earlier are usually homebound due to lack of related specific care service and their condition rapidly deteriorates. This highlights the inadequacy of existing dementia-specific social support.

Some people may say that existing general elderly care service are also enough to serve the needs of dementia caregivers. However, due to the significantly decreased cognitive and self-care ability of dementia patients, the much higher staff to elder ratio would hinder it from addressing individual needs of dementia patients. The lack of attention to every demented elder can lead to rising occurrence of accidents involving demented elders wandering off from the centre while not knowing about the way back. Dangers can be induced like a 79-year-old demented man was killed by a minibus on his way leaving the elderly home alone in August 2016.31

2. Accessibility of social support

The accessibility of existing social support also remains low which hinders its effectiveness.

2.1 Insufficient information and promotion of support

Information concerning different types of social supportive measures are not widely promoted and easily accessible enough for caregivers. As reflected various researches, for instance, WC Chan (2010), pointed out that a considerable amount of family caregivers found the accessibility of social support unsatisfied which lower its effectiveness. Ms. Li, a dementia caregiver, also expressed concerns and frustration when saying that she simply had no idea of where and how to find any dementia-specific social support in the beginning few years. Even if there is actually some useful resources available in society, it would be a waste if family caregivers have

31 Hong Kong home for elderly probes how man with dementia left building before he was killed in traffic accident (21/8/2016); South China Morning Post; http://www.scmp.com/news/hong-kong/law-crime/article/2007061/hong-kong-home-elderly-probes-how-man-dementia-left
no medium to get information about their existence. Therefore, the accessibility of existing social support should be raised through promotion through diversified means.

### 2.2 High cost of services

The high expenses of using the services also lowers its accessibility to caregivers. For example, the cost of attending a day care centre ranges from $400 per day, which equals a large monthly expenditure of $12400. Obviously, not everyone can afford it, especially for those from low-income families.

Some people may claim that the Pilot Scheme on Community Care Service Voucher for the Elderly can be helpful in the sense that subsidies can be provided. However, only 3000 of these vouchers are issued each year\textsuperscript{32}, which only constitutes around less than 3\% of the total number of patients. Caregivers may not be able to bear the heavy financial burden and thus would not opt for the service. Moreover, even if a caregiver receives the voucher, the voucher cannot be used at some of the NGO centres. Re-thinking on the proposed government scheme is required to solve the problem on affordability, which can then raise the accessibility of current social support.

### 3. Usefulness of social support

Due to the low adequacy and accessibility of the social support, only a small proportion caregivers can actually utilize the service. Among this group of caregivers, they indeed find the dementia-specific services, though in limited amount, useful in alleviating their burdens. Therefore, such useful supportive measures should be expanded in scope to cater more caregivers’ needs.

The spectrum of dementia would lead to difference in usefulness of social support as reflected in WC Chan (2010).\textsuperscript{3318} Caregivers of persons with milder dementia found day care service more useful while carers of late-stage dementia consider residential care services the best long-term care arrangement.

\textsuperscript{32} Community Care Service Voucher for the Elderly; Social Welfare Department; retrieved from http://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_csselderly/id_secondphase/

\textsuperscript{3318} WC Chan (2010); Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study; East Asian Arch Psychiatry; 163-168; http://easap.asia/journal_file/1004_V20N4_p163.pdf
There are certainly areas for improvement. A common counterpoint is that some organizations such as Jockey Club Centre for Positive Ageing does provide training courses specially designed for dementia caregivers, claiming that it can provide effective solutions and support for caregivers in response to their needs and difficulties. However, the average frequency of these kinds of training courses is usually only 5 to 6 times a year, each lasting for around 2 hours. The usefulness of such support would be lowered as the 10 hours of training seems unlikely to provide consistent effective support to caregivers.

**Future directions for service enhancement**

To further enhance the supportive effect of the existing measures, the following actions can be taken in the hope of building a closer support network between the society and dementia family caregivers.

1. **Dementia outreach service**

   In Hong Kong, it is common to see elderly spouses being family caregiver of dementia patients. However, their health condition may not allow them to bear the heavy workload of round-the-clock care. Even there are day care centres, they may not have the physical ability to accompany the demented person to the centre every day. Therefore, there is certainly a room for expansion of outreach service to provide home service for the demented persons so as to relieve caregivers’ distress and maintain physical well-being of them, achieving more sustainable caregiving.

2. **Appointment of a “resource person” for each dementia caregiver**

   An accessible ‘resource person’ who can be a nurse, social worker, occupational therapist can be useful. By playing a direct service provider role, caregivers could obtain information and advice about specific aspects of caregiving at once. When need arose, referrals to appropriate agencies can also be made. Such ‘One-stop’ service could provide practical information and contribute to the relief of carer burdens and prevent ‘burnout’.
3. **Online promotion on social platforms**

With the advancement in technology, promotion of social support should not remain only in paperwork, but should utilize the fast transmission characteristic of the Internet. Services can be **promoted on social platforms** in which caregivers with frequent access to Internet can easily obtain relevant information, increasing the accessibility of the existing social support.

**Conclusion**

As our population continues to age, number of dementia patients is expected to be increasing and thus, the needs and support to their family caregivers are increasing. This enquiry highlights the common source of caregiver strain and various unmet needs of family caregivers in Hong Kong. After the evaluation of existing social support, I would comment it as insufficient support, which should be extended in accessibility and adequacy. Only by achieving the above criteria, the usefulness of the support can be truly utilized.

Family caregivers constitute the backbone of dementia caregiving. It is therefore important to understand their experiences and needs for social support, which can help social care professionals to design effective interventions in future to alleviate their burden, leading the society to achieve ‘healthy ageing’ in foreseeable future.
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2. Hong Kong home for elderly probes how man with dementia left building before he was killed in traffic accident (21/8/2016); South China Morning Post; http://www.scmp.com/news/hong-kong/law-crime/article/2007061/hong-kong-home-elderly-probes-how-man-dementia-left

**Book:**

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Appendix 1: Interview transcript with Ms. Li

Interviewee: Ms. Li
Role: A dementia family caregiver, whose father has been diagnosed with dementia for more than 7 years
Date of interview: 18/4/2017

Transcript:

Background information
1) Can you tell me about your father’s medical history of having dementia? What are the current symptoms?

My father has suffered from dementia for more than 7 years and he is now with late-stage dementia in which he cannot recognize everyone including his family members.

2) Are you a solo caregiver for your father, or do you share care with other family members?
   a) (If share with others) How is the work distributed?

   My mother and I take care of my father but most of the work are shared by my retired mother. In recent 2 years, as my father suffered from stroke before, his mobility decreased significantly in these few years. We then hired a domestic worker to share the workload.

3) What is the daily care arrangement for your father?

   As we can't really heavy workload of taking care of my demented father round the clock, my father is now living in a residential elderly home.

4) How much do you know about dementia?

   I don't really know much about dementia, mainly the symptoms and patient needs.

5) How do you obtain the relevant information?

   At first upon diagnosis, I searched online for information like from the webpage of Hospital Authority. Besides, I also asked my friend who is a psychologist about the
causes and treatment for the disease.

6) Do you find the existing information concerning dementia sufficient and easily accessible? How can these knowledge facilitate your caregiving process?

Existing provision of information about dementia is fairly acceptable. However, for older caregivers such as spouses of the patients, they may not know how to use computers so it may be difficult for them to search information online.

7) Have you faced/ are you currently facing problems in organizing your daily routine because of your caregiver role? How do you handle it? Did you seek help from professionals?

At first, it really affected my daily routine a lot as my father always felt anxious when he realized that he forgot things repeatedly. He felt insecure and he always had to stay closely with my mother and me. This caused quite a lot of interruption to our daily routine. As years passed, we got used to it and learned to arrange our time well to balance the caregiving work. But I think I did not really seek help from professionals like social worker at that time.

8) Has the caregiving experience caused any psychological and physical challenges to you?

My mother suffered from depression in the first year of caregiving as my father had to stay with her all the time, leading to insufficient rest and great pressure.

a) If yes, did you seek help from professionals? Are they easily accessible?

Luckily, I noticed my mum had symptoms of depression in early stage and I immediately accompanied her to see the doctor. It was quite accessible and my mother soon recovered after several treatment and counselling.

9) Have you learned how to care for a person with dementia?

I think no… I don’t really know that there’s actually some training programmes which are specially designed for dementia family caregivers.

a) If not, how do you tackle the problems encountered?

I only went for some support groups which mainly targeted on elderly care but not specifically to dementia. When I encountered problems, I sometimes tried to seek advice from friends or social workers or search for information from the
10) If hiring a domestic helper for caregiving, is your domestic helper equipped with specific care skills for taking care of a dementia patient? Has she received any special training on this?

I have hired several domestic helpers before to help take care of my father. But unfortunately, none of them have received any special training on dementia caregiving.

11) As a caregiver for a person with dementia, have you received any social support? If yes, could you please tell us what sort of support you usually receive and whether you are satisfied with these services?

12) Do you find the existing social support sufficient? Are they easily accessible?

Definitely not sufficient! The demand is so high and the existing supply simply cannot meet that demand. Moreover, in terms of accessibility, I think in present, most caregivers who get to know about the services ask for help by themselves. However, I think social service professionals should also be active and take the initiative to give relevant information to caregivers.

13) Do you think the existing social supportive measures such as day care and counselling service useful in solving your caregiving burden? Why?

I think they are mainly useful as they can share my burden and provide advice when I face difficulties. However, I think the adequacy is simply too low which its usefulness cannot be fully utilized.

14) Could you give some suggestions to health professionals and policy makers in order to have better support for dementia family caregivers in terms of?

a) day care service or residential care service?

I think it is really a good idea to have dementia-specific services. More dementia day care centres should be provided by changing the operation modes of some existing general elderly centres. Government should also provide more subsidies to support these services.

b) caregiver skills training?

This is really important as if the caregivers don’t know how they should
communicate with the patients and keep asking them questions, this will only
cause a huge burden to the patient psychologically. More dementia caregiver
skills training programmes should be organized to teach us some knowledge on
cognitive training, communication skills etc.

c) counselling and support service?
More support groups with dementia family caregivers as members will be very
useful as similar experience would surely offer more useful insights. For
counselling, I think social workers should also be more active to provide related
information but not only on request.
Appendix 2: Interview transcript with Ms. Esther Tsang

Interviewee: Ms. Esther Tsang
Role: A social worker providing elderly service
Date of interview: 15/4/2017

Transcript:

1) *Could you introduce your roles in handling cases with dementia family caregivers?*

I have been working as a social worker specializing in elderly service for more than 10 years. When encountering cases with dementia family caregivers, my most significant role is to provide professional supportive counselling according to the subject’s specific needs and background. Besides, my roles also include making referrals and introducing suitable resources services from local support group.

2) *Could you explain the importance of the role of a dementia family caregiver in the patient’s recovery process?*

A family caregiver has a very important role in the patient’s… we can’t say it’s a recovery process as dementia cannot be cured completely by now, but it serves as a significant role in alleviating the patient’s psychological and physical conditions. This is because family caregivers are the persons whom the patients have the closest relationship with, so the patient will place confidence and trust in them. Family caregivers can thus provide emotional support, supervise daily medical treatment such as taking drugs. They can also accompany the patient to join activities held by support groups, extending their social network.

3) *What difficulties or burdens are most commonly found among dementia family caregivers?*

The most commonly found caregiver burden is the psychological stress they encountered. As dementia patients often require constant attention of daily activities, the caregivers themselves may not have enough rest after the long-hour caregiving work. If support and guidance are not given in time, they may develop huge psychological stress and this can even result in psychosomatic problems.
4) **How often do you encounter cases in which the caregiver is under observable caregiver stress in terms of psychological or physical stress or both? How would you handle the cases?**

I encounter both cases quite often but I think those with psychological stress are a bit more common. I would usually provide supportive counselling and making referral to support groups. Apart from these, if I can observe that the caregiver has unbearable psychological stress, I would recommend respite residential service provided by some NGOs which allows dementia patients to live for short term like for around 1 to 2 weeks. Caregivers can then have a short rest to relax themselves. However, the waiting queue of these services is also quite long in which they may need to wait for more than half year.

On the other hand, for physical problems, this often happens to the family caregivers who live together with the patients. The 24-hour work and especially some demanding physical work like carrying the patient around would cause huge burden to them. Psychosomatic problems can also be resulted when overstressed.

5) **Do they usually seek help from you or other professionals on their own initiative?**

I think this is somehow difficult to tell you exactly as this depends on the characters of the caregivers.

6) **What are the major social support that mostly accessed by family caregivers, provided by both government and non-governmental organizations,**

   a) **caregiver skills training?**

   Majority of existing elderly day care centres only provide general caregiving skills for elders like rehabilitation exercise, but not specially designed for dementia caregivers. Provision of dementia-specific caregiver training is not sufficient in amount. In Hong Kong, the work by The Charles K. Kao Foundation for Alzheimer's disease is comparatively much more comprehensive which can act as a future direction for dementia support service.

   b) **for alleviating psychological and physical stress of caregivers?**

   Caregivers usually can only opt for some psychological counselling or support groups services provided by the general elderly care centres. The specific needs and concerns of dementia family caregivers may not be addressed clearly.
7) **How can family caregivers get to know about these social support available in Hong Kong? Is it easily accessible?**

They can seek help from social workers, elderly centres and Integrated Family Service Centres. Accessibility is fair but supply cannot meet the high demand.

8) **In comparison with the rising number of dementia patients in Hong Kong, how would you comment on the existing social support’s effectiveness in alleviating dementia family caregivers’ burdens in terms of its accessibility?**

   a) **accessibility?**
   
   Not easily accessible to all caregivers. More promotion of the support services should be provided.

   b) **adequacy?**
   
   Significantly inadequate which cannot meet the rapidly rising demand.

   c) **usefulness?**
   
   The existing social support is indeed quite useful for supporting dementia family caregivers, however, due to the limited supply, only a small number of caregivers can receive the support. Thus, the scope should be expanded.

9) **What improvements can be made in order to build up a better supporting network between dementia family caregivers and various supporting organizations in the society?**

   Government should increase the resources allocated for dementia family caregiver support so as to alleviate their stress. Moreover, more promotion should be given through different means, focusing on caregivers' informational need. With better knowledge about dementia, caregivers can be better prepared and more ready to offer care. They can also know more about how they can get relevant social support. Lastly, for elderly centres in different communities, more specific caregiver training or support groups can be provided.
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| S1         | AB 9   | ● The candidate demonstrated a well-planned enquiry framework by explaining clearly the criteria for evaluating the support for dementia caregivers, i.e. adequacy, accessibility and usefulness in enhancing the quality of life of dementia caregivers, and adhered to this framework closely in the enquiry process.  
● In Parts A and B, the candidate was able to clearly explain the significance and the aims of the enquiry study. Relevant concepts were considered. However, more abstract concepts such as responsibility, sustainability, and empathy, etc. should have been referred to. Focus Questions 3 and 4 could have been narrowed down further.  
● Highly relevant data regarding support for families with members suffering from dementia were collected from various sources, e.g. a social worker, dementia caregivers, newspaper reports on cases of dementia patients and government documents.  
● In Part D, evidence-based arguments were put forward by triangulating the findings from the interviews and secondary sources and considering various viewpoints, demonstrating an ability to think from multiple perspectives.  
● However, more supporting data and relevant overseas experiences could have been drawn upon for the part on ‘future directions for service enhancement’ so as to achieve a set of more justified and relevant concluding recommendations.  
● The candidate acknowledged his/her sources clearly in footnotes and made good use of various formats to present the information systematically, e.g. graphs.  
● The report exemplified a high standard of enquiry, especially in the integration of various sources of data, resulting in a logical and well-structured enquiry study as a whole. |
|            | CD 9   |          |
|            | PO 9   |          |

*AB:  Problem Definition and Identification of Concepts/Knowledge (Parts A and B)  
CD:  Explanation and Justification (Parts C and D)  
PO:  Presentation and Organisation (the whole report)