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Enhancing Early Recognition and Management of Dementia for the Aging Population of Hong Kong – Roles of Primary Care Providers

如何加強香港老年人口腦退化的及早診斷與治療
– 基層醫療服務提供者的角色

FINAL REPORT

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LIST OF ABBREVIATIONS

APN	Advanced Practice Nurse
BPSD	Behavioural and psychological symptoms of dementia
DCSS	Dementia Community Support Scheme
DECC	District Elderly Community Centre
DH	Department of Health
FHB	Food and Health Bureau
GOPC	General Out-Patient Clinic
GP	General practitioner
HA	Hospital Authority
MoCA	Montreal Cognitive Assessment Test for Dementia
NEC	Neighbourhood Elderly Centre
NGO	Non-governmental Organization
OT	Occupational Therapist
PCP	Primary Care Physician
PHO	Primary Healthcare Office
PPP	Public-Private Partnership
SOPD	Specialist Out-Patient Department
WHO	World Health Organisation

EXECUTIVE SUMMARY

Abstract

Background: Population ageing and increasing prevalence of dementia has become a global public health concern. The proportion of elderly aged 65 or over in Hong Kong will double in 25 years, and demented elders will increase from the present 70,000 to 200,000 in the same period. Despite no known cure, both local and overseas studies revealed the majority of patients' preference for an early diagnosis of dementia, while health authorities and experts all advocate the benefits of early intervention to reduce psychological distress, improve quality of life, slow down the progression of cognitive decline, and prevent premature institutionalisation. To that end, a model that advocates community-based healthcare and social services as well as collaboration among primary care physicians (PCPs), psycho/geriatricians, nurses, social workers, occupational and physical therapists is central to the care of the elders with dementia. As the first point of contact and gateway to specialist services in the current healthcare system, the PCPs play a critical role in detecting early symptoms of dementia, diagnosing, referring patients to specialist care, providing follow-up consultations, devising long-term management plan, and facilitating patients and caregivers to access community support services. While such modes of practice have been endorsed by local and international health authorities, there are practical problems concerning healthcare professionals' training, service integration and accessibility, incentives and medical-social collaboration in Hong Kong.

Objectives: To explore the views of health and social care providers, patients and their caregivers towards the current modes of practice in dementia care, the barriers encountered, the training and incentives needed; to identify gaps in the medical-social collaboration and recommend improvement measures with emphasis on enhancing the roles of PCPs in early diagnosis and management.

Methodology: A qualitative study approach employing focus group and individual interviews was adopted to explore and solicit the views of service users and healthcare professionals on the diagnosis and management of dementia and related health problems in primary care settings. A

total of 10 focus groups, including 6 groups of health professionals, 2 groups of patients with dementia and 2 groups of caregivers; and 8 individual zoom/ telephone interviews with either health professional or patient, or patient together with caregiver, were conducted. All participants were recruited via referrals and the group/individual interviews were audio-recorded and transcribed for content analysis. The focus group discussions each lasted between 1 and 1.5 hours while individual interviews were about 30 – 50 minutes. NVivo software was employed through which designated themes were deductively coded from the data collected and elaborated for analysis.

Results

Ten focus group and 8 individual interviews were conducted with a total of 57 participants recruited, including geriatricians, psycho-geriatricians, PCPs, nurses, social workers, occupational therapists, caregivers, and dementia patients. Participants in the healthcare professional group either worked at public hospitals, private clinics or NGOs, including both frontline and management level, all of whom had extensive experiences in training or rendering services to dementia patients. The private PCPs had all attended postgraduate training programme in community geriatrics and actively involved in district level community care. The caregivers' spouse/parent and patients in our sample had all been diagnosed of dementia, with years of illness ranging from 2 to over 10 years.

Qualitative findings from the interviews were grouped under four main areas, followings are the key findings:

- Help-seeking barriers and enablers in primary care settings

Barriers that impeded patients/caregivers' reception or help-seeking for services related to dementia included their resistance to recognise the symptoms which affected their cognitive and daily functioning, the lack of knowledge and information about the illness and available community support/resources, perceived incapability of the PCPs to manage dementia, negative experiences with primary care services which engendered distrust, impact of Covid-19 that led to service suspension and negative emotions, structural barriers that rendered study participants ineligible for services, the problems of demand greater than supply and issues with service continuity and quality.

A number of enablers were also identified that facilitated help-seeking in patients. These included family support with a caring and attentive caregiver, severity of symptoms that urged the caregiver/family to seek outside help, a capable middle person/agent that connected the patients/caregivers with medical/social support, service impact of quality dementia services, proximity of the caring and training provisions and tangible government support for medical and community care.

- Medical social collaboration

The roles of different healthcare professionals were highlighted and discussed during the interviews. There was consensus that the role of geriatricians and psycho-geriatricians in the diagnosis and management of dementia was indispensable, while some would agree that PCPs were also capable of performing assessment for mild cases, ruling out reversible conditions and assessing the specific needs of each patient, helping them better accept and understand the illness, handling caregiver stress and symptoms control, following-up on dementia cases ‘stepped down’ from SOPD, and accompanying the demented patient/family throughout the journey by continuity of care.

Concerns were also raised about the time and provision constraints that limited PCP’s role in dementia care and problems in their collaboration with the specialists which was essentially a one-way communication. Social workers and nurses in the focus groups also shared similar views, it was pointed out that each profession might not be very clear about others’ work and operation, and there was the need to be proactive, to introduce one’s services to others in order to enhance collaboration and lead to win-win situation.

Currently, the burden of providing community/social support was placed on the NGOs and DECCs in the community. The need for a road map or pathway to guide the next steps and list out what resources were available was expressed. These included the need for a centralized scheme/list to facilitate PCPs referring community services for patients, the gaps and connection from one type/round of service to another, a one-stop website for patients/caregivers to navigate and look for relevant services, and the projection of service needs for dementia in the long run.

- Dementia Community Support Scheme (DCSS)

The contribution of DCSS as a model for medical-social collaboration was recognised by the participants. Concerns regarding its scope and eligibility were raised as the Scheme only served diagnosed dementia patients referred from public hospital specialist services with little or no BPSD symptoms, while the bulk of those most in need were not included. In certain districts, the 50-service quota was not filled up owing to eligibility, transportation and service-boundary issues. It was suggested that greater flexibility in the referral system would ensure resources not wasted.

Moreover, attitude change among the NGOs in the community was observed and greater attention was given to the needs and situation of dementia patients. While the APN was regarded as a capable middle person that connected the patients with the care providers and facilitated collaboration within the DCSS, two or multiple-way communications was also advocated. Lack of planning and funding for post-DCSS care was another concern raised by the participants.

- Enhancing roles of PCPs in early diagnosis and management of dementia

To enhance PCPs' role in facilitating early diagnosis and management especially during the early stages, suggestions were made to install management directive which assigned higher importance and more resources/support on dementia care to PCPs in the public sector, and setting up of a dementia platform at the district level that facilitated communication between NGOs and PCPs.

Moreover, initiatives and funding support from the Government to provide incentives for PCPs to look after patients with dementia were also essential. Reimbursement policy which motivated PCPs to enroll in further training on dementia/community geriatrics and made it a prerequisite for looking after elder/dementia patients. Offered vouchers for patients to visit PCPs with community geriatrics training and undertake radiological imaging or laboratory test to facilitate early diagnosis.

Regarding caregiver support, providing counselling during consultations, sharing online training materials and community support information with the patient's families/caregivers, educating caregivers about the patients' dementia, and helping them with stress management were areas that PCPs capable of. Suggestions were also made to develop tools and scores for PCPs to facilitate their monitoring of patients' chronic conditions predisposing to dementia.

Conclusions: Dementia is an illness that involves both medical and social care. Apart from specialist care, the primary care providers also play a significant role to facilitate early diagnosis and treatment of an illness that entails a long-term care burden on the families and society. Mechanisms to ensure greater participation of primary care providers in dementia care include efforts at various levels: continued training for PCPs, nurses, social workers and OTs as well as caregivers who would shoulder most of the caring responsibilities in both short and long term; joint effort in the form of public and private partnership scheme and specialists and PCPs joint clinic; provisions for PCPs and DECCs to make direct referrals to DCSS; and setting up of medical-social platform at district level to enhance communication among hospitals, PCPs and local NGOs.

Keywords: ageing population; dementia; Dementia Community Support Scheme; medical-social collaboration; primary healthcare

研究摘要

背景: 人口老化及腦退化病例激增已成全球關注的公共健康議題。未來 25 年，香港長者人數倍增，腦退化患者亦會由 7 萬增至 20 萬人。本地及外國研究均顯示患者希望盡早得到診斷，早期確診及治療有助他們延長在社區生活，避免過早入住院舍。有見及此，業界及當局均鼓勵長者護理服務採用社區為本模式，並強調跨界別協作的重要性。其中基層醫療醫生更可發揮關鍵作用，包括疾病診斷、專科轉介、門診跟進、協調社區支援及製訂長期管理計劃。要落實上述模式便須解決有關培訓、不同專業及服務之間的融合及協調等問題。

研究目的: 本研究嘗試針對腦退化症，探討公眾、醫護及社福界對現行服務模式的意見，當中的不足及困難，和所需的培訓及激勵措施，尤其著重如何加強基層醫療醫生早期確診及治療的角色。

研究方法: 本研究採用定性方式, 透過小組討論及個人訪談，收集服務使用者、醫護及社工專業人士對及早診斷與治療的意見及與基層醫療相關的問題。前後共安排10次聚焦小組，其中6組為醫社專業人士、腦退化病人及照顧者各2組，另有8次個人訪談，均以zoom或電話形式進行。所有參加者均透過轉介招募，每個聚焦小組為時約1至1.5小時,個人訪談則約30至50分鐘。討論及訪談內容全程錄音後轉錄成文字，數據再經由NVivo程式進行分析。

研究結果

本研究先後進行 10 次小組討論及 8 次個人訪談,參與總人數為 57，其中包括老人科醫生、精神科及基層醫療醫生、護士、社工、物理治療師、照顧者及腦退化病人。醫護及社工的受訪者來自公立醫院、私家診所及社福機構，其中包括前線及管理階層，並曾參與培訓或腦退化職務。私家醫生均曾修讀社區老人醫療深造課程並積極參與社區層面的照顧服務。另病人及照顧者的家屬均為已確診腦退化的患者，病齡約在 2 至 10 年或以上。

- 向基層醫療服務求助的障礙及有利因素

病人/照顧者的求助障礙包括他們抗拒承認自己患病並影響認知及日常生活，對腦退化疾病及社區支援/服務缺乏認識及資訊，不認為基層醫療醫生適合治療腦退化，基層醫療服務求診的負面經驗帶來不信任，新冠疫情令服務暫停或中止，結構規限未符資格接受服務，或因服務供過於求以及延續性、質素等問題。有利求助的因素則包括家庭支援特別如果病人擁有細心及高效的照顧者，病情惡化致家人須向外尋求協助，把病人/照顧者與醫社支援連繫起來的中介人或機構，優

質的腦退化服務讓病人及家屬看到果效，服務及訓練設施地點方便及獲得政府資助接受醫社服務。

- 醫社合作

針對腦退化治療，受訪者均同意老人科及老人精神科醫生扮演關鍵角色，但亦接受基層醫療醫生可以發揮積極作用，包括為輕症患者進行評估，排除逆轉因素，了解個別病人的需要，協助病人及家屬接受患病，處理照顧者的壓力及情緒問題，跟進從專科門診下轉的穩定個案，及陪伴病人/家庭走完整個療程。然而，基層醫療醫生因受診症時限、病人數量及醫療設施所限，往往未能發揮應有功能，與專科醫生之間又多為單向溝通。受訪的社工及護士對此均表贊同，並指出各個專業不一定了解其他界別的工作及運作，故須作出主動溝通加強協作，達致雙贏局面。

目前，社福機構及長者地區中心負起提供社區照顧及支援的重任。受訪者認為有必要製訂路線圖，方便基層醫療醫生為患者轉介社區服務，了解服務與服務之間的不足及連結，並提供一站式資訊平台讓病人/照顧者獲取資訊，以及推算長遠服務的需求及發展。

- 智友醫社同行計劃（智友計劃）

由於現時智友計劃只限經由公營醫院專科轉介的輕度病人參與，受訪者對計劃涵蓋的範圍及服務對象的資格甚表關注，擔心許多有需要的病人未能受惠。然而，亦出現部分社區的服務限額尚有餘額，主要由於資格不合、交通和地點偏遠及服務範圍規限等問題所致。建議彈性處理轉介機制，確保資源不被浪費。此外，智友計劃的推行亦令社福機構對腦退化患者的關注提高，從而因應病者需要提供更適切的社區支援及服務。此外，受訪者均同意資深護師能有效發揮連結病人與服務提供者的功能，及協調計劃內不同持分者之間的合作，但亦同時提出雙向、多向溝通的重要性，以及對智友計劃終結後缺乏後續計劃及資助的關注。

- 加強基層醫療醫生的角色

為加強基層醫療醫生在促進腦退化及早診斷及治療的角色，並提供實際支援，建議於公營醫療投放更多資源及關注於腦退化治療及服務，並在地區層面設立腦退化服務平台，促進社福機構及基層醫療醫生之間的溝通及協作。此外，政府亦須製訂政策及提供財政援助，鼓勵基層醫療醫生接受腦退化治療的進階培訓，並發放醫療卷讓病人向社區內具相關資歷的醫生求診及接受評估。

為照顧者提供情緒輔導，向病人家屬/照顧者提供網上培訓教材及社區支援資訊，幫助他們了解

腦退化的病徵及進程，以及學習紓緩壓力的方法，亦是基層醫療醫生能發揮所長之處。預防工作方面，建議發展適用於基層醫療的監測工具及系數表，協助監察病人長期病患的情況，並預防惡化引致腦退化疾病。

研究結論: 腦退化疾病對家庭及社會均帶來長期負擔，極需要醫社協調的治療及支援。除專科診治之外，基層醫療服務提供者亦扮演重要角色。為加強醫社合作及各個持分者參與照顧及治療，實有賴多方的合作和努力，這包括為基層醫療醫生、護士、社工、職業治療師及照顧者提供持續培訓，透過公私型協作計劃、專科及基層醫療醫生聯合診症，擴大智友計劃的轉介途徑、於地區層面設立醫社平台，加強醫院、基層醫療醫生及社福機構的溝通和聯繫，長遠減輕長者服務的負擔。

關鍵詞：人口老化；腦退化；智友醫社同行計劃；醫社合作；基層醫療

Summary on Policy Implications and Recommendations

Based on our findings, the following recommendations are proposed for the consideration of the HKSAR Government and medical authorities:

1) *Public education to raise awareness about early diagnosis and management*
Systematic measures and publicity campaigns that emphasise dementia care at the primary care level by family doctors and NGOs with good community support will be useful to raise public awareness. An '*Early Diagnosis Programme*' that provides free or subsidized cognitive assessment by private PCPs with geriatric training is recommended. Public education with emphasis on prevention of dementia by good maintenance of the '3-highs' (diabetes, hypertension, and hyperlipidemia) should be launched.

2) *Subsidise continued and further training in dementia care for PCPs*
Government involvement and funding support or reimbursement policy for higher training in community geriatrics and dementia care will be good incentives to encourage more PCPs to share the burden of specialist care in dementia.

3) *Enhanced care for the caregivers*
To enhance the biopsychosocial well-being of caregivers which can be done by PCPs during medical consultations. Respite and outreaching services to caregivers with greater care burden and constraints, and online apps and training materials for the younger caregivers should be designed and financially aided.

4) *Expand Public-Private Partnership Prgoramme (PPP) to include dementia treatmen*t
A provision to enable stable dementia patients to receive care from PCPs with geriatric/dementia training in the community and helps shorten the waiting time for specialist care at the SOPD.

5) *Set up Mini-joint Clinic at GOPC*
Based on the current mini-joint clinic model, special sessions at the GOPC will be allocated for

joint consultation by PCPs and psycho/geriatricians to enable early diagnosis of patients' memory problems and reduce the need and waiting time for referral.

6) *Expand community care voucher usage to include assessment services*

To expand the scope and provisions of community care vouchers to enable patients to visit PCPs with community geriatrics training and undertake radiological imaging or laboratory test for early diagnosis, and those who prefer homecare to receive day care services in the community.

7) *Enable different sources of referral for DCSS*

To revise the referral mechanism and allow PCPs and NGOs involved in dementia care to make direct referrals to DCSS. This helps facilitate patients' accessibility to the Scheme as well as other primary care services and community support.

8) *Establish mechanism to facilitate two-way communication between medical and social sectors*

Setting up of a medical-social platform at the district level with formal structures and mechanism for exchange and two-way or multiple-way communications among the different healthcare professionals.

9) *Long-term projection and route map*

Funding support for research activities and service innovation in dementia, and to explore the need for a mass dementia screening programme among the 65+ group which will provide useful figures for long-term projection and an overall route map that links up different service packages and provisions for dementia care.

政策影響及建議摘要

根據以上研究結果，現提供下列建議供香港政府及醫療當局考慮:

1. 加強公共教育，提高大眾對腦退化疾病及早診斷及治療的意識。建議推行「早期診斷計劃」，由私家醫生提供免費或資助的認知評估服務，並提倡減三高防腦退化的口號。
2. 政府提供資助及製訂相關政策，鼓勵基層醫療醫生持續培訓，加入照顧腦退化患者行列。
3. 加強對照顧者的支援，提供促進生理、心理及社交健康的診症服務，並因應照顧者需要設計網上培訓程式及教材。
4. 擴大公私型協作計劃增設腦退化治療，由基層醫療醫生照顧病情穩定的患者，縮短專科服務的輪候時間。
5. 於普通科門診診所設特別時段，安排基層醫療醫生及專科醫生聯合診症。
6. 擴大社區照顧券的使用範圍，涵蓋認知障礙的評估服務，並為選擇居家患者提供日間中心服務津貼。
7. 增加智友醫社同行計劃的彈性，接受基層醫療醫生及社福機構轉介的病人參加。
8. 在地區層面，建立促進醫社合作的雙向及多向溝通平台及機制。
9. 推算長遠腦退化服務需求及發展，鼓勵調研、服務創新及製訂路線圖，並考慮為65歲或以上人士推行大型檢測服務。

INTRODUCTION

With the ageing of the population worldwide, the increasing prevalence of dementia has become a global public health issue. There are over 55 million people worldwide living with dementia in 2020 and the number is expected to reach 78 million in 2030. In Hong Kong, approximately 8.4% of adults aged 65 or above (103,000 elders) are affected by dementia in 2009 (1). A significant increase in local prevalence is highly likely as Hong Kong population enjoys the world's highest life expectancy (2). According to the Census and Statistics Department, the proportion of elderly aged 65 or over in Hong Kong is going to double in the next two decades, from 1.17 million in mid-2016 to 2.45 million in mid-2039. At that time, the estimated number of elders with dementia will be more than 200,000.

Dementia, a chronic syndrome characterized by progressive decline of cognitive function that interferes independence in activities of daily living, often has a profound impact on not only the persons diagnosed and their immediate family (3), but also their extended family and social network (4). Dementia is not restricted to only cognitive impairment and functional decline, but also behavioral and psychological symptoms including delusion, disinhibition, violence, irritability, and yelling (5). Currently, there is no cure but pharmacological and non-pharmacological interventions that help to delay the functional deterioration for dementia are available. Evidence to support the use of pharmaceutical agents or dietary supplements in preventing Alzheimer's had remained insufficient (6). Some pharmacological interventions, for example acetylcholinesterase inhibitors, are found to have better efficacy in ameliorating symptoms in the early stages of dementia. Besides, psychoeducation for caregivers that started earlier in the disease course could be effective in improving caregivers' mood and quality of life. For maximum intervention options and benefits, timely detection and identification of dementia becomes the key. Evidence revealed that early recognition of dementia could reduce psychological distress of both patients and their families (7, 8), while advance planning and persistent treatment during the mild-to-moderate stages of dementia could slow down the progression of cognitive decline (9-11).

Public attitudes towards early management of dementia

International studies show that community perception of dementia is mixed. One meta-analysis reported that some patients and their families were very distressed about the possibility of dementia. Their fear and reluctance to face the disease had resulted in delaying the timing of diagnosis (12). In other studies, patients were generally agreeable to dementia screening, especially if they understood the benefits of early identification (13, 14). A recent study in Australia suggested that people rather wished to be told about the diagnosis as soon as possible, regardless of demographics or any personal relation to dementia patients (15). Our study on local Chinese respondents also showed that they preferred to access treatment and support early for dementia. Nearly two thirds of the respondents perceived practical issues (61.3%), physical health (61.0%), and emotional distress (58.4%) as their most fearful impacts (16). These problems would require both medical and social support.

Management of dementia in the primary care setting

The Mental Health Review Report (17) released from the Food and Health Bureau in 2017 highlighted that more than half of the dementia cases managed by the Hospital Authority (HA) were mild to moderate. The report emphasized that:

> *People at this stage are in transition between healthy, active life and frailty. This is precisely the time when intervention, especially at the primary care and community level, should be given to prolong the progression of their disease so that patients can stay in the community for as long as possible. It will also reduce unnecessary and premature admission to infirmaries, hospitals and residential care homes, and in turn improve their quality of life before reaching the severe stage of dementia.*

In other words, community-based primary care physicians (PCPs) can play a pivotal role in the care of the elderly (18). Relatedly, the World Health Organisation (WHO) and the Alzheimer's Disease International had also promulgated a Seven-stage Model (17). Not only does the model identify the multiple needs along the continuum of dementia care from pre-diagnosis to end-of-life palliative care, it also emphasizes the importance of ongoing and long-term care service provisions. The advantages of strengthening primary care for mental health problems have been widely acknowledged, including holistic care, first-contact care, continuity of care, affordable cost, easy accessibility and less stigma (19). As the first point of contact and the gateway to specialist services in the healthcare system, PCPs are capable of detecting early symptoms of dementia, diagnosing, referring patients with dementia or suspected cases to specialist care for further investigation, providing follow-up consultations for mild to moderate cases in the community and arranging appropriate community support (17, 18). They should be able to discuss the long-term management plan with the patients and their caregivers, and facilitate them to access available services such as occupational therapy, speech therapy and other support centers in the community (20, 21). The PCPs can also educate the patients and caregivers about other risks brought about by the disease, such as cardiovascular risk factors and encourage exercise, socialization and cognitive training (22). All in all, the PCPs may encounter, and have to manage, dementia's complexities brought by patients or their caregivers more frequently than just regular follow-ups.

While the above concepts and advocacy on dementia care are generally recommended by the HA and Primary Healthcare Office (PHO) of the Food and Health Bureau (FHB) (17, 23), what is at stake is how much has been implemented in the current health and social care context? To answer this question, we need to know more about what support is needed to enable the PCPs to perform their roles adequately, what are the barriers and enablers that deter or encourage patients as well as their caregivers to seek the appropriate services for their needs, what kind of collaboration or service integration or delivery model are needed if early recognition and management of dementia are to be effectively delivered in the community.

Current barriers to early recognition and management of dementia in Hong Kong

Theoretically, primary care for dementia in Hong Kong covers private clinics of PCPs, general out-patient clinics (GOPCs) under HA, elderly health centers under DH, elderly community centers, day care centers/units for the frail elderly, and also community care service teams and integrated home care service teams (17). However, various practical barriers to fulfill their expected functions have been noted. Our earlier study found that PCPs tended to overlook symptoms of early dementia. While most PCPs could recognize memory loss, misplacing objects, disorientation, mood changes and personality changes as typical dementia symptoms, other also common but early symptoms including apathy, loss of initiative, a failing sense of direction, restlessness, and distraction were least recognized (24). Besides, about 75% of primary care services are provided by the private sector where support from other healthcare professionals is lacking compared to that of the GOPCs, despite HA's intention to develop public-private partnership for dementia care (17). For the elderly community centers, they provide general support for counselling, rehabilitation, social and recreational activities rather than specific care for dementia. The day care centers, on the other hand, provide cognitive and memory training, reality orientation and reminiscence therapy which cater more for the specific needs of dementia persons, and yet the number of recipients were only around 4,500 elders as of December 2016 (17). It is important to know whether existing services are well integrated (18), easily accessible and known to the patients and their caregivers, and most of all, meet their needs for early recognition and management.

A previous local study found that most decisions on residential care application or placement were made against the wish of the person with dementia or the caregivers. The key factors included worries over health deterioration of the person with dementia, actual unmet care needs and behavioral issues that exceeded the physical and mental capacity of family caregivers, as well as the lack of available community support (25). Our recent studies also found that it would be difficult for the caregivers alone to look after the physical and psychosocial needs of the person with dementia (26-27). They are in need of continuous advice and support from health and social care professionals throughout the progression of dementia.

Conceptual framework of the dementia care pathway in Hong Kong

Services for dementia care are currently provided by the government, non-governmental organizations (NGOs) and the private sector. Patients with dementia symptoms often need to be encouraged and accompanied by a family member to seek help. The family caregiver often acts as a coordinator to search for health and social care services. On top of all concerns, the first step is to recognize dementia symptoms before further cognitive decline takes place. Despite the public's accepting attitude towards an early diagnosis of dementia, their knowledge on dementia and its available services may affect their help seeking behaviours (28). Another recent study of the research team also found that caregiver-reported but not self-reported symptoms predicted clinical severity (29). This indicates the crucial role of caregivers in dementia recognition and help-seeking.

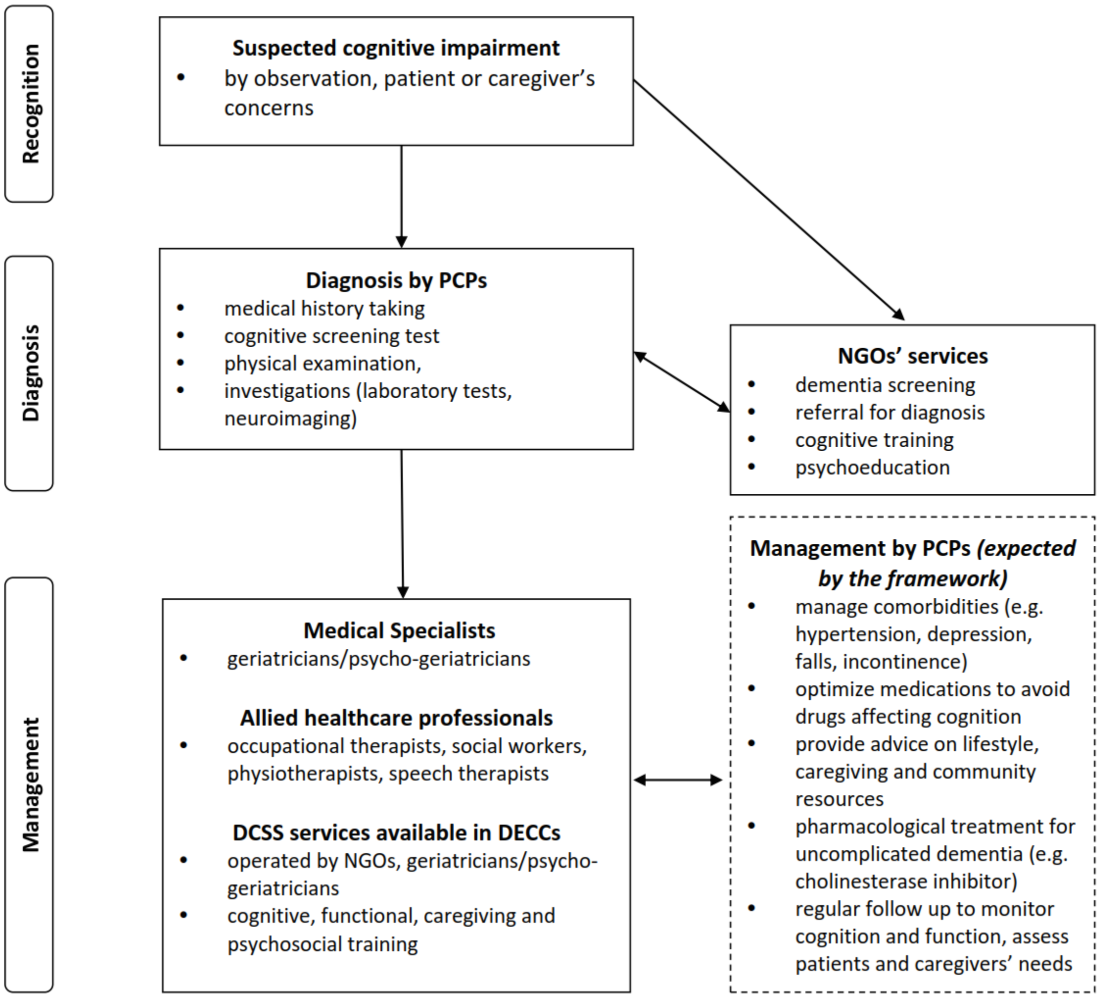
Latest international studies found that more than half of the respondents' primary point of access to dementia care was the PCPs (55.8%), and the median time between initial care and arrival at the specialist services was 48 weeks (30). In Hong Kong, patients seeking help from PCPs would undergo initial cognitive assessment and preliminary laboratory investigations. The PCPs may then refer the patients to psycho-geriatric or geriatric clinics for further assessment and management, if indicated. The usual waiting time for these specialist services often takes more than a year (31). The PCPs face significant challenges on the services required by the patients during this period. Patients and their caregivers may also seek help from NGOs for necessary services.

In the local system, the NGOs but not the formal medical services have been playing a major role in promoting early recognition and management of dementia. NGOs, founded by charity fund and operated in self-financing mode, provides one-stop dementia care services for patients at different stages of their illness, including cognitive assessment and on-going care and training for both patients and caregivers (32). The services they provided are comprehensive but also expensive, which does offer a viable option for those who can afford though not the majority of patients and families.

In recent years, there is a number of government initiatives which aim to enhance care for the elderly and those with dementia. The "Dementia Community Support Scheme" (DCSS) launched by the Food and Health Bureau provided dementia community support services in District Elderly Community Centres (DECCs). DCSS has been regularized in all 18 Administrative Districts since 2019. It is a collaborative scheme involving all 41 DECCs, operated by NGOs, and HA's geriatricians and psycho-geriatricians. Each DECC provides services for 50 demented patients, totally serving around 2000 mild to moderate dementia cases (33). The DCSS demonstrates a collaboration model between medical care and community social services. Elders who have been diagnosed with mild to moderate dementia by (psycho-) geriatric teams of the HA are referred to this scheme. Patients and their family members may attend workshops and support groups to train up their cognitive ability and self-care ability. Despite the benefits reported from the patients and caregivers, a significant drop-out rate was noted in some centres that only 1/3 of participants completed in one of the NGOs, while initial refusal to join/default rate was also 1/3. PCPs by far have no involvement in this Scheme (34).

Despite the multitude of dementia services provided by different parties/organizations, it is unsure whether these services are well interconnected and brings about optimal outcomes, and whether they are readily accessible by the public, health and social welfare professionals. Integrating the information described above, we illustrate the current dementia care pathway by a flow diagram (Figure 1) modified from the assessment and management framework of cognitive impairment in older adults proposed by the PHO (23).

Figure 1: Conceptual framework of dementia care pathway in Hong Kong
(modified from the algorithms for Assessment and Management of Cognitive Impairment in Older Adults in Primary Care Settings, proposed by Primary Healthcare Office of the Food and Health Bureau)



Remarks:
PCPs – Primary care physicians
DCSS - Dementia Community Support Scheme
DECC - District Elderly Community Centre

Potential strategies to enhance collaboration and service integration

We have seen projections on the demand for elderly care and especially dementia, in order to ensure planning and development are geared towards the right direction, and prevent overburden of our current and future medical and social capacities, it is important to explore the views of key stakeholders on how to enhance collaboration as well as integration and availability of the services. Currently, most of the early management tasks are provided by NGOs and pilot programmes of the Government such as the DSCC, while the PCPs are involved more in referral tasks than ongoing management and follow-up especially during the period after initial diagnosis and before attending specialist care. To explore strategies to meet the expected roles of PCPs in dementia care as stated in the framework by PHO is also one of the focuses of this Study.

Moreover, enhanced collaborations between primary care and specialized care services provided by geriatricians and psycho-geriatricians are important to improve the quality of community care and shorten the waiting time for specialist clinics. Furthermore, medical-social collaboration should be emphasized. The medical and social needs of people with dementia vary widely as the disease progresses. Dementia care is known as a labour-intensive task involving multi-disciplinary healthcare professionals (17). Opinions from social workers, nurses, occupational therapists and physiotherapists are essential for an integrated and efficient system for dementia care in the community. Yet, there is currently little information about their views and experiences in collaboration.

OBJECTIVES OF THE STUDY

1. To understand patients and caregivers' barriers and enablers to help-seeking for dementia in the primary care setting from early to later stages of dementia.
2. To explore views of primary care physicians (PCPs), psycho/geriatricians, social workers, nurses and allied healthcare professionals towards the current modes of medical-social collaboration and recommend improvement strategies for dementia in primary care.
3. To explore the views and experiences of caregivers and health professionals on Dementia Community Support Scheme (DCSS).
4. To devise strategies for enhancing the roles of PCPs in early diagnosis and management of dementia, particularly on:
    - 4.1 Service support to PCPs on diagnosing and managing dementia
    - 4.2 Incentives for PCPs to look after patients with dementia
    - 4.3 Designing patients' management plan in the community with nurses and social workers
    - 4.4 Enhancing support to the caregivers
    - 4.5 The potential role of PCPs in DCSS
    - 4.6 The role of PCPs in identifying reversible conditions to prevent mild cognitive impairment from progressing into dementia.

RESEARCH METHODOLOGY

The study adopted a qualitative approach to explore and solicit the views of service users (including patients diagnosed with dementia and their caregivers) and the healthcare professionals on the diagnosis and management of dementia and related health problems in primary care settings. Both focus group and individual interviews were employed for data collection which took place between March and December 2021. Owing to the Covid-19 situation, the interviews were mostly conducted via Zoom except for the two patient focus groups which were face-to-face, and several telephone interviews were also made for patients/caregivers who were not familiar with using online media.

Participant recruitment

A total of 10 focus groups, including 6 groups of health professionals, 2 groups of patients with dementia and 2 groups of caregivers; and 8 individual zoom/ telephone interviews with either health professional or patient, or patient together with caregiver, amounting to 57 participants were held. The 10 focus group discussions each lasted between 1 and 1.5 hours, while the individual interviews were about 30 – 50 minutes. Table 1 below shows the composition of each focus group and individual interview.

Table 1 Composition of focus groups and individual interviews

Composition of focus groups		Composition of individual interviews	
Group 1	6 Public PCPs	Via Zoom	
		1	Private PCP
		2	Geriatrician
Group 2	6 Private PCPs	3	Geriatrician
Group 3	4 Nurses	Via Telephone	
Group 4	3 Social workers + 1 nurse + 2 Occupational Therapists	4	Patient and her sister (caregiver)
Group 5	3 Geriatricians + 2 Psycho-geriatricians	5	Patient and his wife (caregiver)
Group 6	3 Geriatricians + 2 Psycho-geriatricians	6	Patient and her daughter (caregiver)
Group 7	4 Caregivers		

Group 8	4 Caregivers	7	Patient
Group 9	3 patients	8	Caregiver
Group 10	3 patients		

Recruitment of health professionals were done mainly by the Investigators who helped invite geriatricians, psycho-geriatricians, public PCPs, nurses, occupational therapists from public hospitals as well as district elderly community centres; and social workers from NGOs to join the interviews. Private PCPs who had their own clinics or worked in group practice were also invited to take part in the interviews. The invitations were sent out either via emails or through direct phone calls from early March 2021 onwards.

Besides health professionals, Investigators also helped recruit patients and caregivers to participate in the study. Invitation were made to patients who had been diagnosed of dementia during their visit to memory clinics, psychogeriatric clinics or geriatric outpatient clinics, and their caregivers. NGOs that offered community support and training services to dementia patients, and community nurse who paid home visits to patients, were also invited to refer suitable participants to take part in the study. To ensure the unique perspectives of the patients with dementia, they were arranged to share in separate focus groups from the caregivers. For those who were hesitant to talk in a group environment, individual telephone interviews were offered instead. Each participant was offered supermarket/book coupon as incentive for their involvement.

The patients in our sample had all been diagnosed of dementia, with years of illness ranging from 2 to over 10 years. Except for four patient participants (3 focus group participants and 1 telephone interviewee) whose thoughts were still clear and coherent, and able to reasonably communicate, the responses of the other patient participants were brief and easily lost focus. When that occurred, as in three of the telephone patient interviews, their caregiver stepped in and supplemented information/details to the questions of the interviewer.

Procedure

As the main bulk of interviews were conducted either via zoom or telephone, participants were contacted and confirmed by email or phone of their participation. A zoom link was sent to them prior to the event for online connection. For the 2 face-to-face patients focus groups, the first one was conducted at a University of Hong Kong venue, while the second one was held at the NGO where the participants were recruited. Except for the telephone interviews which were conducted by 1 interviewer, all the other interviews were moderated by 2 interviewers with higher qualifications in social work and counselling, audio-recorded and then transcribed for further analysis. The accuracy of the transcripts was checked by one of the investigators against the audio recordings.

During the interviews, open-ended questions were asked to prompt participants' responses towards the following topics, and the discussions were moderated according to the actual flow of the exchange.

Topics for discussion:

Health professionals (Psycho/geriatrician, PCP, Nurse, OT, Nurse)

a. Dementia patients' trajectory of diagnosis and management – role as a health professional
b. Medical-social collaboration
c. Roles of PCPs and primary care providers (NGOs) in the care of dementia patients
d. Limitations, service gaps
e. Incentives and improvement strategies
f. Comments/experiences about government schemes (DCSS) for dementia patients

Caregivers and Patients

a. Trajectory of diagnosis – role as a caregiver
b. Experiences in receiving community support services
c. Barriers/difficulties and enablers in taking care of dementia patient / help-seeking
d. Perceptions/experiences about PCPs or primary healthcare service in dementia care
e. Comments/experiences about government schemes (DCSS) for dementia patients

Data processing and analysis

The data collected was analyzed using NVivo software version 12. Employing a content analysis approach, coding categories were deductively derived from the Study objectives and text data were coded based on these categories. The completely transcribed texts of the interviews were entered into the database and coded into the designated themes after repeated reading of the transcripts and listening to the audio-recorded interviews. An indexing structure was established to further develop the themes and new codes were also added inductively when the transcripts were being coded, resulted in a framework of themes and subthemes after repeated discussion among team members. The data were coded independently by two team members who are experienced in qualitative research. Comparison between the two sets of codes showed consistency among the majority of them. Inconsistencies were resolved by discussion between the two coders to reach agreements on common themes and names or labels of the codes.

RESEARCH RESULTS

Participants recruited in focus group and individual interviews

In total, 46 participants were invited to 10 focus groups (3-6 participants per group), including 14 male and 18 female health professionals, 8 female caregivers, 3 male and 3 female patients. In addition, there were 8 individual interviews conducted with 3 doctors, 4 patients and 4 caregivers, all female except 1 of the patients being male. The caregivers aged 53-75 with a mean of 63.6 years, the patients aged 61-90 and the mean was 75 years old.

Participants in the healthcare professional group came from different disciplines and both public and private sector were included. The psycho-geriatricians and geriatricians were recruited from local public hospitals while the public PCPs were from GOPC under the Hospital Authority. They included both junior and senior rank of medical staff. The private PCPs, with years of practice ranging from 17-41, had all attended postgraduate training programme in community geriatrics and actively involved in district level community care. The nurses were either Advanced Practice Nurse (APN), senior nursing officers or community psychiatric nurses working in Hospital Authority, and NGOs rendering dementia services. The 3 social workers came from DECC while the 2 OTs who had extensive experiences in training and rendering services to dementia patients, worked at public hospital and NGO respectively. Details of the demographical information are presented in Table 2.

Table 2. Demographic information of interview participants

Socio-Demographic	n	
Total number of participants	57	
Focus group interviews	46	
Individual interviews	11	
Occupation		
Health professionals	35	
Caregivers	12	
Patients	10	
Gender	Male	Female
Health professionals	14	21
Caregivers	0	12
Patients	4	6

Age	Range	Mean
Health professionals		
Caregivers	53 - 75	63.6
Patients	61 - 90	75.0

Qualitative findings from the interviews were grouped under four main areas as stated in the Study objectives, namely, help-seeking barriers and enablers in primary care settings, medical social collaboration, DCSS, and roles of PCPs in early diagnosis and management of dementia. Selected quotes and extracts from the participants were added to support the main findings. Participants' demographic information was provided after each quote in a bracket, which included: identifier of participants (whether in focus group or individual interview) and his/her interview number, gender (Male/Female), age, and occupation/status.

I. Help seeking for dementia in the primary care settings – Views of caregivers and patients

As indicated from their sharing during the focus group/individual interviews, all except two participants had experiences of participating or receiving services at the primary care level, either attending day care centre, district elderly community centre, being a DCSS participant, or consumed paid dementia training services from NGOs. While their participations were to different degrees and durations, a number of barriers were reported which impeded their reception or help-seeking for services related to dementia. These included patients/caregivers' subjective and perceptual barriers, objective barriers induced by experiences and the environment, and structural barriers imposed by the healthcare system.

Barriers

1.1 Patient resistance

Patients/caregivers' resistance to recognise the illness (dementia) and the effect it brought to themselves and their daily living had caused delay, at least initially, in seeking help to deal with the emerging symptoms of dementia, such as memory decline, confusion, and change in temperament. In the case below, the patient disregarded those symptoms and was unwilling to consult his family doctor even when urged by his wife (*Caregiver 9*) to do so several times. It was after about a year that the wife decided to accompany him to the PCP at Department of Health's Families Clinic did the husband get referred for further assessment.

> 咁後尾我又靜雞雞幫佢做個 test 填下，我填完之後就覺得... 佢就係 borderline 嘅，即係如果 100 分 50 分合格，佢可能係有時 49，有時 51。後，我估佢都 test 左成一年，終於我嗰年就叫佢... 因為我哋係公務員，我就叫佢睇 Families Clinic，後尾不停提佢。佢因唔係我又去睇醫生，又覺得自己 capable。我就不停咁提佢話，你話俾醫生聽你乜啦，但佢唔肯講。如是者有一次我唔理佢，我話我都 book 咗去睇醫生，我就同佢入去醫生度，我寫咗張紙自己提佢，我話你同醫生講啦，佢同醫生講咗。醫生就話唔緊要啦，佢抽血驗下先，跟住佢都寫咗張 referral 俾我哋。 *(Caregiver #9, telephone interview, female, aged 65, retired, patient/husband 69 years old)*

Patients' resistance, especially among the males in our study, was related to their strong hold to autonomy and the ability to self-care, the loss of which was perceived as disastrous for them. The father described in the case below was one such example.

> 他是很抗拒接受治療。… 他就很抗拒。就是因為他不是很接受自己是有腦退化。他真的體會到自已記不住東西了。而他那個自主權是拿得很緊。… 然後就是，初期就是吃半粒藥，那麼他對於要食藥呢，即是吃這一種是說可以增強他腦袋，沒有那麼差，他是很抗拒。… 因為我媽媽是直接的照顧者啦，還有提醒他，在這方面，令到他很不接受。不接受自已真的這麼差。即是那個記性，還有日常的生活也做不到。*(Caregiver #8, focus group, female, aged 58, housewife, patient/father 87 years old)*

Another focus group male participant who enjoyed an active lifestyle (e.g. hiking, gardening, yoga) also downplayed the effects of the disease on him, he claimed that

> 有時東西忘了，是不出奇的。有時不用緊張事情，是有一些東西不用記的。不用那麼認真啦。
>
> 現在我們坐在一起，像是每一個人都很有活力的。我們好像精神爽利，沒有問題的。我們說話，大家也沒有斷纜。⋯ 如果你有認知障礙，你說話不會那麼暢快的。是不是。說話也是會有一些紊亂的。*(Patient #3, focus group, male, aged 73, retired from his commercial business)*

Besides, he also boasted about his self-help techniques and not relying on a regular doctor (PCP) to manage his different illnesses (Diabetes, hypertension, high cholesterol, heart problem, prostate, cognitive problem), instead he opted for the specialists, partly because of the insurance coverage to which he was entitled.

> 我有什麼事，便會立刻看醫生，我不會說那麼多事。…那麼是要弄清楚我哪一個器官不好，我每年也是會驗一次器官的。我付了錢給保險公司，心肝脾肺腎都驗了
> 所以我老婆問我小小事就常常看醫生，我看了，我就是可以睡得著了。就是這個原因。
> 自己知自己哪裡不妥，便去吃藥。
>
> NGO 是什麼？未曾去過。我是通常自己上課的。如果是有興趣班，我是會上的很多的。看相又去，電腦又去。… 其實這些呢，是自己救自己。你在家就是多一點做事。消磨了時間。即是我在家，會弄一些木欄、花園啊那些。圍桿，那些植物……*(Patient #3, focus group, male, aged 73, retired from his commercial business)*

1.2 Lack of knowledge and information

For those who showed little resistance to help-seeking, such as Patient #1 in one of the focus groups who was eager to look for ways to slow down the progression of her dementia,

> 那麼我是想請問，除了我剛剛說的，繼續喝 supplement，還有是打麻將之類，舞照跳，歌照唱以外，我還有沒有什麼可以做的？即是令到這件事，再延緩它的進度，即是肯定就會進步的，即是越來越嚴重的那類，但是我想它慢一點。或者是有什麼方法可以……即是有沒有… *(Patient #1, focus group, female, aged 61, housewife)*

the lack of knowledge or information about the community support/ services available, and the usefulness of training activities rendered by primary care providers, "Never heard of NGO's training activities. Do not know about that, probably because not much publicity. Should be the case, otherwise, nobody knows." had barred them from reaching out for help at the primary care level.

> 我覺得是…即好似斷定了…誒，自己是得了這個…有這樣的情況啦，已經得了這個這樣…所謂的病…即屬於病啦，甚麼腦退化的病。那都好似無甚麼、無甚麼求助的方法。（哭）…好似都是聽天由命。
> 即這些都不是一朝一夕，同時都不是說…我們有甚麼渠道可以去求醫或者有甚麼能力去求…關於這一方面的普通的…誒，已經…老人家已經是太多病的了，對眼又、又甚麼，還有身體其他的部份，關於腦這個…在我自己來講…好似是…好奢侈的病。（哭）
> *(Patient #7, telephone interview, female, aged 72, retired)*

The patient in the above case shared her helplessness in looking for training and community support services. Despite being referred by the hospital geriatrician to attend training activities, she was put on waiting list by the NGO that specialized in providing services for people with dementia. Her concern of not to over-burden her daughters with her illness, and her inability to search other available resources within the community she resided added to her frustration. Nor did she think joining activities at community centre would be useful in her case.

> 有的，但是我覺得社區中心幫助不大的，因為社區中心都是多數讓老人去活動下，但是
> 誒…即如果有關於這些…都屬於是一個病來的，就…他們未必是會…誒，甚麼的。
> …我就覺得期望不是這麼大了。因為…政府那些…甚麼社區中心都是玩玩下那樣多些。
> *(Patient #7, telephone interview, female, aged 72, retired)*

The same issue about the use of non-pharmacological measures for dementia patients was raised by one of the private PCPs in the focus group too,

> 他們[caregivers]不會覺得，不會知道帶他去[NGO]做什麼，不知道帶他去有什麼作用，
> 每月也要去付錢，但是去到是做什麼呢，只是玩遊戲啊，好像不知道做什麼。
> 因為這些，其實我們……我們當然知道是有用，但是我們如何溝通得到，讓病人家屬知
> 道不光是[靠]用藥。 *(Private PCP #3, focus group, male)*

While it might not be realistic to expect patients with dementia to be capable of seeking help for themselves, the burden often fell on their close ones/caregivers. Caregivers in both focus group and telephone interview also mentioned about the difficulty to sort out relevant and useful information which was not readily available to laymen like them.

> 其實都難找的，我有很多朋友講我知我才知道的…同時我有上網看一下啦。見醫生那時
> 醫生有講過啦。最近去那個 XX 會那裡呢，那裡有位姑娘就經常都講我知，同時有個社
> 工哥哥都好好。那就有多些資料，否則就是…即之前是没有的。*(Patient #8's sister,*
> *telephone interview, patient female, aged 68, retired)*

1.3 Perceived incapability of PCPs to manage dementia

Apart from unfamiliarity with dementia services, participants' perception of PCP's role and abilities had also dissuaded them from seeking help from their PCPs both before and after diagnosis. The perception that PCPs were only for treating cold and influenza, and not capable of managing or suitable to be consulted for dementia led the caregivers/patients to go straight to the specialists.

> 沒有沒有沒有[經家庭醫生]。因為知道她也是老人科那些病症。因為媽媽看家庭醫生，她也是傷風感冒那些才去看，因為她自已不喜歡吃那麼多藥的。所以她不是有什麼大的病痛的樣子。… 所以看到她的 symptoms，我們是立刻請教四周所有的朋友，四處去問。那麼便會知道，似是應該這個老人症的了。所以我們立即去看那個老人科醫生……*(Caregiver #7, focus group, female, aged 69, housewife, patient/mother 89 years old)*

> 但是一看到我媽咪那些…嗱，好簡單，傷風感冒就無甚麼所謂啦，但是你一去到老人家有些血壓糖尿心臟，那我、我又不是好夠膽…即我又不是好信任得到我、我個 family …即 family med 那位、那位醫生。 *(Patient #9's daughter, individual interview, female, patient 72 years old)*

In the above case, the daughter (caregiver) of the dementia patient concurred with and gave full trust to her mother's cardiologist who thought a family physician was not the suitable person to take care of a patient with multiple illnesses.

> 她有認知障礙又有睡眠窒息，又…即各樣病，那我這位心臟醫生，他直情話：「不好了，不如你心臟…你就算頭暈身慶，感冒甚麼，你都來看我啦。」因為他驚…你普通 family med 或者不知她個 background…成呎厚個 background，你求其給了些傷風感冒藥她吃，她不適合啊。*(Patient #9's daughter, individual interview, female, patient 72 years old)*

As another caregiver pointed out, PCPs was not of much help in dementia cases and Hong Kong's general practitioners needed to be better trained, even a senior nurse might do the job better.

> 即我覺得香港的 GP 好…好…誒…好無甚麼用… 即不是要人特別好關心，而是…你應該…即你知多些講多些，誒、譬如個 patient 個問題你講給他聽，可能一兩次你不知道，但是你見到他那個 symptom，你都知大約可能會是甚麼，你都會 warn 他們。那變得…香港的醫療那些 GP 就真的要提高水準，如果你問我就…可能 senior nurse 都超級好過他們。*(Patient #8's sister, telephone interview, patient female, aged 68, retired)*
>
> 問題就是可能會不會其實家庭醫生 or 普通科醫生其實沒有這樣的一個認知啊? 所以當他們，他那個病人，看的時候，就是說我發覺 daddy、mommy 有這樣的狀況，就是好像 P3 的家庭醫生，就是說她可能抑鬱而已。她可能是身體不好啊。但是反過來，他[GP]對認知障礙症有認識的話，那麼就會提到她，便會知道。*(Caregiver #2, focus group, female, aged, patient/, 68 years old)*

1.4 Negative experiences with primary care services

Actual experiences also reinforced their impression of how PCPs rendered their care to the patients. The above caregiver continued her criticism regarding continuity of care and treating symptoms instead of person,

> 我覺得他們不是幫到手，尤其是如果你「打散」，因為家庭醫生…之前我們住這個屋苑啦。我之前看開的醫生，他没多久，又不知是走了抑或「執笠」，我都不記得了。就換了另一個醫生。個醫生比較年青些, 就「打散」的，他不會經常見到你，即他…即他不是看慣了的，就差好遠的。
>
> 你看慣了的，可能、可能有些感情，以前我在港島住呢，看慣了一個醫生。是…他都知道了…即有了 record。你有甚麼事他都…即他都會有少少 heart，即是說，你可以怎樣，你甚麼…這樣；但如果你不是看慣了呢，是…「哦，你頭痛呀？好，開些止痛藥給你；哦，你傷風，給傷風藥你。」*(Caregiver #2, focus group, female, aged, patient/, 68 years old)*

In another case, the caregiver thought that the PCP was unable to make an accurate diagnosis and confused the patient's dementia for depression. Despite the fact that it could be difficult to differentiate a patient with depression, especially severe depression, from dementia at the beginning, the case here reflected the caregiver/patient's mistrust of the PCP's medical judgement.

> 那麼她看醫生，她不吃東西，醫生覺得是她是抑鬱病，給她一些抑鬱藥。那麼我覺得不是這樣。但是那時候沒有辦法，因為沒有出事，不知道怎樣……即是覺得她是抑鬱，就是心情不好，就是抑鬱，以為她是情緒病，就是這樣啊，沒有處理啊。
>
> 直至她自己是抑鬱到不吃東西，不吃東西到要進醫院，才 check 到出來。
>
> *(Caregiver #3, focus group, female, aged 63, working part-time, patient/mother 90+ years old)*

> 其實你問……即是你回答剛剛的問題，就是說社區，即是我一直看的那位家庭醫生有沒有用，其實用途不會很大…。因為，叫他去看，就算我有醫健通，他們是可以看到他的 record 也好，其實是某個程度上，其實看醫生也是不會去理會到這個……那麼我是反而覺得社區的幫助是很大的，即是好像是……是因為我覺得社區的 support，是真的比所謂醫院好。*(Caregiver #2, focus group, female, aged 58, retired, patient/father 93 years old)*

1.5 Temporal barriers – Impact of Covid-19

Owing to the Covid-19 pandemic in the past two years, many of the NGO's facilities and training activities catered for dementia patients in the community were closed or cut short, patients needed to resort to online activities and communication, which might not produce similar benefits as in person treatments. The patients also received less stimulation in daily life and resulted in greater resistance to return to training.

> 但是我比較擔心的是，其實在疫情期間，是差了。因為中心有時沒開放。那麼他上課呢，剛剛也分享了，就是上堂的時候，我覺得他是好一點的。但是他停了，沒有上課之後，即使讓他再上課，他也不願意。他常常覺得他自己畢業了。*(Caregiver #2, focus group, female, aged 58, retired, patient/father 93 years old)*

> 因為 Covid 停了一陣子，幾個月回去社區活動的樣子，那麼沒有去的時候，就整個人呆了。覺得是更差了，例如她計數是很叻的。她很喜歡計數，常常搶答，活動的時候。現在是計數不能，然後就因為沒有活動很久啦，已有年多，沒有什麼活動，就差了。…otherwise，如果她是沒有 Covid，一直 keep 著，其實她是應該 stable 的。

> 例如剛剛你們問，電腦的那些活動，因為我媽媽是真的沒有興趣。見到電腦，她就沒有興趣。那麼去了中心回來，那些活動叫他們活動手腳呢，其實是很悶的。
> 即是你「一、二、三、四、五、六、七、八」的樣子，她沒有心思做，我都沒有心思做。
> *(Caregiver #3, focus group, female, aged 63, working part-time, patient/mother 90+ years old)*

1.6 Structural barriers – Eligibility

Other than temporal or incidental barriers which might change over time, there were certain structural or long-term features that discouraged patients/caregivers' help-seeking attempts in primary care settings. Eligibility to services was one of them.

> 因為我也曾經申請社區那些呢，希望他可以下午去吃一餐飯這樣子，那麼我輕鬆兩小時這樣子，是不是？但是也不合格啊。即是他要計分啊，還是欠一點啊。*(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

> 但是我完全得不到服務。他說你有工人，我們做不到，這樣說。所以這個對我來說，真的很 disappointed。… 為什麼我有工人，就不可以做到這個服務……我只是需要你教我怎樣扶她起來，因為我們怕用錯了力，會影響。那麼他說做不到，所以我們什麼服務也沒有。*(Caregiver #7, focus group, female, aged 69, housewife, patient/mother 89 years old)*

Unable to apply for meal service for her husband, probably because his conditions were not severe enough, Caregiver #6 had to take him to Chinese restaurant for lunch daily and encouraged him to do computer exercise on the tablet at home. In Caregiver #7's case, she had hoped to seek some physio help/advice for her mother whom experienced several falls at home, but was in vain because she was not in the most deprived group.

1.7 Demand greater than supply

Participants shared their experiences that waiting time for community support/services specifically for dementia patients, not to mention about specialist services, was longer than a few years ago. For some programmes, patients had to draw lots to get in.

> 難的。以前就好些。早、早三兩年就好些，現在好…即好多人報[社區那些活動 - 伸展運動]，同時可能它會剔一些…誒…你都上過堂了，那可能就有一段時間就輪不到你了這樣，是這樣。
> 它有些…譬如有些…誒…有些「細藝」給你做下，譬如…有時就開班傾偈，有時就有些手、手、手工給你…穿下、插下那類。總之都有少少東西給你…即消磨個時間，是的。
> 有沒有看法？我們、我們當、當事人來說呢，就好似抽籤，好彩就有，就可以有三個月…我們去上堂，如果抽不到就在家等。（笑）自己、自己消遣，都是看電視。*(Patient #8, telephone interview, female, aged 68, retired)*

> 也是說社區支援是重要的。即是你去政府排期又很久啊、私家醫生也很貴。那麼還有在家附近是方便的。
> 你在社區，但是你看看我住在南區，怎麼找也只是有幾個 centre，要排很長的隊伍。
> 那麼即是入到去打死也不會走的，說真的。把位佔著。是啊。*(Caregiver #1, focus group, female, aged 53, clerk, patient/mother)*

Caregiver also expressed the hope of having day care centre service for the patient, yet the current supply did not meet the need, and the long term costs of care was also a major concern.

> 好似外國，我見到有些就是白天…白天有車來接他過去…即好似返學那樣，五點鐘送他返來，even 沒有車，我覺得你自己安排都不是一個大問題，但是有這些 service 呢…。家人 relief 呢…沒那麼辛苦呢，照顧他們…會照顧得他們更加好些，起碼他們返學了，那我們可以…誒，執拾下東西，幫她買些東西或者想到些甚麼，即會有些時間…會可以照顧得他們好些。對嘛？*(Patient #8's sister, telephone interview, patient female, aged 68, retired)*

> 家人的 feedback 當然說是不夠，他們很多想要 day care，他們日間要上班，又不想放那個老人家一個人在家，覺得他不 safe。
> 但是他們負擔不起請工人，但是 day care，政府那些可能會排隊很久，但是 NGO 那些他們又收費，他們又付不起。*(Geriatrician #1, focus group, female)*

> 是啊，即是花費是一個問題。真的。他們長遠而言，是有很多花費的。日常生活，我想這幾位也是會有的。食啊、用啊、成人尿片也是不便宜的，去到某個階段。藥費啊，如果不是看政府，你看私家的藥費是好貴。*(Patient #8's sister, telephone interview, patient female, aged 68, retired)*

1.8 Continuity and service quality

The impact of Covid-19 on dementia service in the community might be temporal, but the lack of continuity and quality professional support would affect the impact of the community support/services and cause regression in the patients' motivation for training.

> 那麼人手，說真，流動性很大的。你會見到社區中心的姑娘，每隔兩年有時就會換一個姑娘。還有他們是沒有自已的一 team 人，即是職業治療師，物理治療師，那些社區中心是外判 outsource 出去的而已。
>
> 之前疫情的時候，也有一些所謂物理治療師上來曾經探訪，那麼我也曾經跟他們聊天，他們全部也是 outsource 出去，他們沒有足夠的錢聘請一個駐院、長駐在中心的治療師存在。…那麼這些政府，其實政府是可以做的。*(Caregiver #1, focus group, female, aged 58, clerk, patient/mother)*

> 我也曾經看過。即是中心，即是這些所謂社區中心，他們沒有這些 professionals。政府沒有給資源，他們請不到 professionals。就算他們也是憑經驗去幫我們照顧老人家。*(Patient #8's sister, telephone interview, patient female, aged 68, retired)*

Enablers

Despite the barriers mentioned, there were also a host of enablers which facilitated patients and especially their caregivers to seek and receive quality care and services at the primary care level.

1.9 Family support

Based on the responses of the participants in our Study, family support, especially attentive care and keen observation from family member(s) played a crucial role in the patients' help-seeking experiences.

> 那…你一開始…其實無負擔的，即對我來說，我生活…只不過我是…即 be more sensitive。即是…吖，留意多些，或者家裡有些…即刻我就…跟著去裝修家裡了。那你加些扶手呀，個廁所打了個[浴]缸，即之類，你是有些東西 prepare，那是…是好事的。
>
> 那…我都會給少少 credit…給自己，就是，我好早留意到媽媽行為上有些…咦，「鬼馬嘢」喎，…我好怕有些人話：老人家無記性[是]應該。其實我不是很贊成這句話。…因為她除

> 了無記性，是有其他行為上有些表徵你會發現，如果你細心看的話。
> *(Patient #9's daughter, individual interview, female, patient 72 years old)*

> 同埋佢又... 我覺得佢自己唔肯認自己係，唔 recognise 自己。我成日睇啲資訊呀，啲人好努力即係去運動呀，去咩嘅。但佢唔認嘅，即係我講，佢都唔睬我嘅，咁我唯有想佢點樣去做... 即係我有試過帶佢去做譬如馬會咪有啲贊助嗰啲做嘅腦退化嘅健康身體呀，個啲 something like that。*(Caregiver #9, telephone interview, female, aged 65, retired, patient/husband 69 years old)*

In the case below, the daughter, a volunteer for the DCSS who recognised the benefits of community support/services for dementia patients, was able to motivate her father to seek help and attend training activities despite his resistance.

> 我以前會帶他去[中心]一齊玩 game。大家一起玩一些遊戲，跟他一起玩啦，他又 ok。因為可能人多。即是姐姐又可以在他身邊，我又可以在旁邊，如果是上課，家人是不可以在身邊，只是可以老人家跟社工,義工在裡邊。 *(Caregiver #2, focus group, female, aged 58, retired, patient/father 93 years old)*

Most caregivers in our Study would also take the initiative to seek information and service for the patient.

> 想也是要很依靠自己啦，即是有時候你要，你要找就當然要找在自己家附近那些啦。,,, 那些我可能會去看看那些章程呀，是不是適合，適合我便會入會。,,, 那麼我去入會了，那麼他們很多時候，他們也會寄一些章程給我，即是覺得你⋯⋯你如果適合的，你便自己去打電話。現在很方便，你打電話就行了。不需要走去那兒申請的。那麼你入了會，之前就會通知你，那麼你到時到候，就帶長者去參加。*(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

> 可能我們作為一個照顧者，就需要四周去，最好就是在自已的社區，去找一些資料，找社工找你熟悉的朋友，那麼他們也是可以提供一些有用的資訊給我們啊。*(Caregiver #8, focus group, female, aged 58, housewife, patient/father 87 years old)*

The caregivers themselves, also actively sought support from self-help group and connect patient with professionals.

> 除了請教多點⋯⋯如果是能夠多一點那些同路人呢。大家交換的經驗呢，即是自己也會沒有那麼害怕。因為會知道他將會的進程是怎樣。自己怎樣去拿捏，怎樣去了解呢。

> 有時適合我自己去了解舒緩的，或者是一些講座的，也盡量去參加，有一些是很好的。可以讓你帶上患者去的。它有姑娘，就跟幾個人 group 在一起，跟他玩遊戲。我自己就可以很安心的，聽一些講座這樣子。*(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

> 是去到這個月啦，是有一個突破。就是其實我一直在接收的資料啊，我也是去尋求社工的幫忙。還有我自己也會去聽一些講座，還有在網上取得一些資料，那麼增加了我在這方面的知識與認知。那麼我就會跟我媽媽談。這個月就是很好。
> 我媽媽也是願意跟我一起去見社工。而我媽媽也是願意去表達、傾訴她自己所面對，即是照顧爸爸的困難。*(Caregiver #8, focus group, female, aged 58, housewife, patient/father 87 years old)*

1.10 Severity of symptoms

Despite most participants agreed that early diagnosis of dementia was preferred which enabled them to make better preparation, ironically, it was not uncommon that many patients/families would wait till the patients' symptoms became unmanageable would they then seek for help. In the case below, the patient's daughter had to resort to 999 service when her mother's BPSD symptoms became intense. The patient was finally admitted to the hospital and formally diagnosed with dementia. The daughter then quitted her job and cared for her mother at home since she did not want to place her in an old aged home and it was difficult to hire a helper too.

> 她有時會說我拿走了她的東西的樣子。那麼媽媽一直比較小氣的，所以我不為意……然後，但是呢，2018 年啊，年初呢，她就說我常常都聽到人說話，那麼是有幻聽啊。那麼當然我們機靈了，我們知道有一點事啦。我就知道如果真的要 diagnose 的話，可能她要入一些……即是要入精神科啦，所以我不願意呢…
> 有一個星期我覺得很辛苦，就是我預先準備食物給她，下班便立刻回家，但是我因為勸不到她去看醫生呀…有一日，我放工之後，她情緒又不怎樣好，我就忍受不了，我覺得一定要解決啦，因為那時我就 call 了 999。*(Caregiver #4, focus group, female, aged 60, retired, patient/mother)*

Hence, understanding about the benefits of early diagnosis would facilitate dementia patients' help-seeking.

> 我覺得是要早發現，還有照顧者，即是其實好像上課，即是在不斷學習，聽多一點外面的社區中心那些活動，就更可以舒緩到我們面對的壓力。*(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

1.11 A bridge in-between

Patients who attended specialist out-patient department (SOPD) (e.g. psycho/geriatrics, memory clinic) would usually get referrals or urge by the doctors, nurses and OTs to attend cognitive training/activities offered by NGOs in the community. The majority of our patient participants did so under their advice and arrangement. With help from the professionals, like the social workers in the cases below, patients and their caregivers were able to find and benefit from the dementia service.

> 不是，他也是很幸運的。在斷斷續續，在疫情穩定了一點之後，他那個精神科、那個部門就跟[NGO]有一小組，稱為……醫社同行的合作的。他那一位 T sir 呢……我們去覆診，他又見我們，然後就去評估他，他又介紹他到小組，又去三個月的樣子。
> 是啊，是啊。我們這裡，就算是幸運。即是由發病之後，一直也有一點小組，一直跟進。
> *(Carers #5, focus group, aged 75, female, patient/husband)*

> 那麼我是很感謝，有一位社工，他上來，就跟我爸爸媽媽一起做了一個評估，那麼在當中，了解到我爸爸那個特性。……應該經過跟他傾談，了解到他的特性與專長，就是邀請他就是去做義工，就不是去日間中心，那麼就是一個很大的突破。
> 就是讓他可以去了第一次、第一次的日間中心。所以我覺得其實社工在這方面，特別是對腦退化的人，他們有一個比較深入的了解，還有他能夠行出第一步……即是他在這一方面，也是幫助到我爸爸行出第一步。*(Caregiver #8, focus group, female, aged 58, housewife, patient/father 87 years old)*

> 是很多時候因為……[NGO]那些姑娘，即是她可能比較敏銳一點。即是她感覺，不如有這個活動，你就去讓他們去參加。即是比較好像……是我們去得多，就比較了解我們。所以我很感謝她們的幫忙。
> 如果不是，我們也是傻傻地，不知究竟發生什麼事，不知道有這樣的病情這樣子。
> *(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

1.12 Service impact

The positive changes in the patients after joining training activities helped assure families about the benefits of such services and the importance to continue.

> 還有是可能去了中心，人比較 social 多一點了啊。例如是跟她上街，到外面走的時候，例如是早上的時候，去上學的時候，會跟她到外面走走，遇到鄰舍，鄰舍跟她打招呼呢，她也會有反應的。以前，她是不理會人的。
> 即是在不同的 stage 可能需要的東西也不同。…即是如果去參與活動那些，我覺得活動多一點是好一點。即是家人的壓力也會沒有那麼大。*(Caregiver #3, focus group, aged 63,*

> *female, patient/mother)*

> 那麼有數間可以給我挑選，我就選擇了這間，為什麼？因為我知道它[有宗教背景]，又是比較鄰近我家，去起初的十課。初時的兩個月。媽媽也很 enjoy。
> 那麼她便去啦。在這些課堂中是很好的，又會玩遊戲。那麼她是內歛的，但是也有參加。即是給她不同的工作，在一些時間，我也跟她一起去上課。
> 即是我覺得是很開心的，即是我覺得這些 course 是對她非常好的。*(Caregiver #4, focus group, aged 60, female, retired, patient/mother)*

> 因為覺得自已還沒有老啊的樣子，這樣的心態，為什麼要去老人院這些地方。
> 但是他上去[日間]醫院，經過那些姑娘解釋，又說，即是差不多好像洗腦的樣子，那麼去了[日間]醫院三個月，回來以後，他真的改變了好多。每一項東西也會容易接受了一點的樣子。*(Caregiver #5, focus group, aged 75, female, patient/husband)*

1.13 Proximity and transportation

Transportation cost was a concern raised by a few caregivers. They were then able to find similar services in nearby centres which certainly eased the care burden and facilitated the patients to take part in centre-based activities.

> 那個長者中心就是剛剛是在我們居住的屋苑旁邊，所以他才可以這麼方便去到。
> *(Caregiver #8, focus group, female, aged 58, housewife, patient/father 87 years old)*

> ……還有在家附近是方便的。很多老人家不願意舟車勞頓去中心玩數小時，又回來。
> 還有有車接送，是很重要的。那時候，我跟很多中心說了很多次，也說過我找這裡，是因為他們有車。他們說不上是最好的那一間，也不是很差。但是因為有車，我需要有車接送。*(Caregiver #1, focus group, female, aged 58, clerk, patient/mother)*

1.14 Government support

Cash support from the government helped alleviate the financial burden of the patients and families, and also enabled them to utilise dementia services in the community. Participants welcomed such provision which helped make the patients living in the community manageable.

> 其實我也是這年近這幾個月，才拿了什麼優惠券，那麼之前沒有，沒有這些券呢，平時也是一個月接近三千元，那麼還要有剛剛提到……其實她年紀大了，又要有營養奶啊，又有那些尿片，尿布啊，就看看醫生，其他就是……
> 其實一個月那個開支，也是不少啊。那麼就是最近有了那個券，就覺得好一點，即是減了一半左右啊。*(Caregiver #1, focus group, female, aged 58, clerk, patient/mother)*

> 那麼他是很幸運，即是大概等了半年左右，我現在拿到那個政府日間津……即是沒有床位，政府沒有位那些，但是就給了錢、津貼，那些是什麼券，服務券。政府出資，我就每個月出五百多元這樣子那一種。長期。是啊。三百多元一日。所以現在政府給我津貼，上四日，我也是五百多元。*(Caregiver #5, focus group, female, aged 75, housewife, patient/husband)*

> 最好就是有些政府的一種流動[宣傳]車。它就有每一個區的社區活動、社區的中心呀，那些資料。那麼，例如我們大家都知道哪裡、什麼時候，有這些政府流動車。
> 但是有一些不是很熟悉，那麼如果有流動車，那麼我知道什麼時候會有關於這方面的東西，那麼我便去取啦。取了，然後我們就可以直接去聯繫。
> *(Caregiver #6, focus group, female, aged 71, retired, patient/husband)*

II. Medical-Social collaboration – Views of health professionals and Improvement strategies

Medical-social collaboration is important in the case of dementia because it is an illness that requires both medical and social support. The use of non-drug measures becomes prominent especially during the post-diagnostic period. The focus group discussions among the different health professionals reflected how each party perceived the roles of others in the medical-social collaboration picture.

Roles of different health professionals

There was consensus that the role of geriatricians and psycho-geriatricians in the diagnosis and managing of dementia was indispensable despite some would agree that PCPs were also capable of performing assessment for mild cases.

> 我們也是很 pragmatic，即是有沒有一個 option 或是一個 channel 給他們 [PCPs] refer。
> 所以他們也是有一些 work up。
> 他們會…有一部份是會例如 blood test，又或是 cognitive testing，他們也是會做了。
> 幸好他們也是 access 到一些 occupation therapist 做一些 cognitive testing，即是這個對於他們來說，也是 helpful 跟快捷，他 refer 了，等了 results。再加上 history 的樣子，所以我想一些 straight forward 的 dementia，其實也是……他們 [PCPs] 也是很 capable 可以在 clinic 裡做一個 diagnosis。*(Geriatrician #5, focus group, male, consultant)*

Moreover, PCPs were also expected to provide community resources to patients and handle caregiver stress and symptoms control, or to follow-up on dementia cases ‘stepped down’ from

SOPD.

> 在門診，也是見到大部份病人又或是家屬，其實他們對於那個 resources 其實是有限 … 所以這一方面，我是想 at least primary care doctors，除了 diagnosis 之外，其實 resources 的 information 也是這些可能也是 somehow 也是可以 provide 給他們。*(Geriatrician #5, focus group, male, consultant)*

> 即是例如我們也是有一些 case 他們已經 stable 了，他們又不是那麼需要很 intensive 的 psycho-social 的 intervention。其實他們可能只是回來，repeat 一下 anti-dementia medication，那麼如果 primary care 是 ready，那麼我想我、自己 imagine 也是 at least 有兩三成左右，我們自己手上的 case 是可以 step down 到 primary care。是啊。
> *(Psycho-geriatrician #3, focus group, male, consultant)*

> Primary care 在這一部份可能是會 limited 一點，因為如在我們的 cluster primary care 也是有他們的 dementia services，但是很多時候一旦複雜一點又或是多做一些 investigation 的話，就最終也是要回到 SOPD。
> 但是反過來，若果例如是我們在 SOPD 已經是斷症，知道他是 stable 的 Alzheimer's Disease，lewy degeneration，那麼其實 primary care 是可以幫助我們去跟進。
> *(Geriatrician #2, focus group, male, consultant)*

PCPs with experience treating dementia patients also agreed to their role in helping the patients and their families to better accept and understand the illness, and to accompany the demented patient throughout the journey by continuity of care.

> 我覺得很fruitful的是，在diagnostic process中，那個通常也是跟家人一起來，病人narrate他整個memory complaint，日常生活的detail…···其實很多時這些details是病人沒有跟家人提到，而家人也不知道，那麼在病人disclosed的時間，其實是促進了家人跟病患者本身的溝通，也是知道大家的想法，原來大家suffer的地方。
> *(Private PCP #1, focus group, female)*

Another aspect was to rule out reversible conditions and assess the specific needs of each patient.

> 例如是那些病人帶他家人來，我們 as a GP，例如是我 suspect 他有dementia，那麼我覺得最重要是不是age related，是不是那個memory impairment，是不是age related······，我們當然要知的，我們要分到這幾項，然後要告訴病人去處理，我想這一個是幫到病人很多的。
> 如果可以pick up到 reversible的dementia，例如是depression，又或是age，或是其他的例如是thyroid problem那些是稍為少一點的。也是希望可以幫到病人有這一方面的insight.

> *(Private PCP #4, focus group, male)*

> 所以我覺得那一環呢，我覺得是……其實是before那個diagnosis。
> 其實是需要一個比較熟悉這一個病症的醫生去幫他先做一些事情，然後接著發覺即是rule out了，或者真的是都replace了所有他需要要treat的事情，之後就是應該是refer下去給professionals，即是……我覺得應該是個別看看那個老人家的情況是怎樣。
> *(OT #1, focus group, female)*

The PCPs' role to maintain physical and mental health of patients was also seen helpful to prevent health hazards that triggered onset of dementia as pointed out by a senior occupational therapist working in the hospital.

> 那麼我自已覺得其實primary care的醫生，是有角色的。他的角色可能是幫我們去……一些老友記，因為老友記太多。
> 因為你可以看到整個 dementia，其實是很vascular related，即是與心血管很有關係，即是三高啊、DM那些，我覺得definitely其實是在前線醫生。其實如果是做好這一步，其實是幫助到，即是正所謂截了個上遊。*(OT #1, focus group, female)*

Other PCPs, including those working in the public sector, however were more concerned about the constraints that limited their role in dementia care, and they did not find their collaboration with the specialists so promising.

> 我覺得不單是 diagnosis 的。如果到時真的有 resources，真的如果有 CT Brain。有 OT 去 back up，去 social worker 辦 placements，那麼其實就是 management 的角色，which is 我覺得 primary care physician 其實是可以很 comfortable 去 take up 的。
> 如果有 training 跟 resources，**不過我們是在這一刻沒有的**。*(Public PCP #5, focus group, female, frontline)*

Owing to current time and resources constraint, PCPs had little incentive to take up dementia cases, the present GOPC set up and PCPs in private practice allowed little time for them to conduct MoCA (Montreal Cognitive Assessment) nor provision to do laboratory tests.

> 即是一個 assessment，例如真的要做一些……可能是問 OT 的同事，或是其他同事做得比較清楚一點，是在不同的 domain 上做一些不同的 testing 的樣子，那些是要很久的，是要做一個小時以上，所以我們這個是未必有時間。
> 再加上可能做一些 blood test，甚至是 CT [scan] 又或是 MRI。這些對病人來說，可能

> 也是有一些……即是 cost concern。*(Private PCP #3, focus group, male)*

Moreover, patients attending GOPC often presented multiple problems and PCPs might not be able to explore or alert to cognitive problems given the time constraint. The biological chronic illnesses e.g. diabetes, hypertension and hyperlipidemia but not dementia were constantly patients as well as doctors' priority concern.

> …manage dementia 呢，是 very expensive…但是看到的 results 就不是這麼……real，但是你 manage 到 diabetes, manage 到 hypertension, 你是會看到很 positive results 出來的。所以我說呢，人們實際上，你最重要給我搞定血壓，搞定 diabetes，搞定 cholesterol。那個 dementia，佢地 overlook 的。*(Private PCP #4, focus group, male)*

The above somehow explained why most PCPs preferred to write referrals for patients with dementia symptoms to see specialists in the psycho/geriatric departments once they ruled out other possible causes for the patients' problems. Yet, the collaboration with specialists was more like a one-way communication.

> 那麼例如是我有事，現在我除了是可以寫一封信。例如是我現在也是啊，你寫了一張紙 refer 給 geriatric team，你在醫院的時候，我們通常斷了，不知道去了哪裡。就是要等 carer 下一次來看醫生，我們才知道。
> 那麼我覺得這個是可以有改進的空間，我覺得是，即是這個很多時就是斷了又……
> 即是很不幸，我常常覺得是沒有一個整體上 integrated 的 picture，每一個人也是有一個 role 的。*(Private PCP #2, focus group, male)*

Apart from medical diagnosis and treatment, PCPs' role in providing non-drug measures or community support/cognitive training services to diagnosed patients also seemed limited, especially among the private PCPs.

> 問題就是我們如果想病人 refer 去 day centre，即是一些 elderly centre，這個是我們是沒有很多 resources。結果呢，我們又沒有，我們的 resources 是可以適當 refer 一個人去到做一些 cognitive stimulation 那一類的 day centre。
> 這個是對我們單打獨鬥的醫生，其實沒有什麼好好 information at hand… *(Private PCP #3, focus group, male)*

> 但是問題就是第一，你診斷了之後，在診斷過程中，你的 legal aspect，我就有點關心。

> 即是你可能會標籤一個人，你是這樣子，即是你要有confidence，照樣接回來做，即是像我剛剛所提及，你不光是服藥或是貼藥，又或是有時socially，或是日常生活如何做呢，即是那個social worker的support，或者如果有什麼community resources幫助這個呢，我是覺得做醫生在這方面，反而是很空白的。*(Private PCP #5, focus group, male)*

Similar views were expressed among the social workers and nurse focus group.

> 我們有時接一些醫生例如是九龍那邊，便會好一點。他們見到MoCA低分了，就可能就叫他(patient)過來我們中心啦 但是如果出面有些GP其實不是熟悉社區運作的話呢 其實他們就算知道他們的老人家，可能他們的家庭醫生的話，知道他差了，其實他也不是很懂識得跟家屬講去哪兒找服務，可能就是說「你去一些老人中心看看啦，有沒有特別活動啦」。*(Nurse #1, focus group, female)*

From the PCPs point of view, it was the NGOs' who should take initiative to introduce their services to PCPs because they received funding and manpower from the government.

> 那麼……那邊的機構應該主動跟當地那個colleague知道，他們這個services，我們怎會知道他們有這個services? 這個主動權在他手上，他弄一封信來也好，說我現在得到這樣的funding，有這個資源也好。
>
> 問題是他拿著資源，錢在他手上，OT也好，PT也好，social worker在他手上，那麼access這個資源的時候，我們怎會知道他有什麼服務的，沒有理由的。他introduce服務給我們，我們才會知道的。*(Private PCP #2, focus group, male)*

A social worker, in charge of a DECC agreed that each profession might not be very clear about others' work and operation, and there was the need to be proactive, to introduce one's services to others in order to enhance collaboration and lead to win-win situation.

> 我同意的。因為其實好視乎醫生的背景。醫生是不是熟悉那個服務，或者知不知DECC或者地區層面，就是剛剛例如說的一些可能是改善家區服務服務隊，究竟是做什麼，其實反而醫生是很專注於他們自己的醫療上的東西。
>
> 反而社會服務呢，其實大家…你問我，其實我也不認識醫生的運作。所以其實他也未必認識我們究竟在做什麼。我覺得好多時候 這一步，其實我同意是仍然有一步去再邁進再向前行的。*(Social worker #1, focus group, female)*

> 可能我們定時有一些單張send給他們，他們見到字面寫了什麼，他們就如是的去介紹case，介紹給patient，反而我覺得作為DECC，其實我們要再走多步。其實我們也聯絡了hospital那邊職業治療部，不如會不會我們上來介紹一下，告訴醫生或者告訴OT，我們DECC 相應有什麼類似的服務，你遇到類似哪一類的朋友、client，其實可以轉介過來，

> 那麼我覺得大家是一個 win-win situation。*(Social worker #1, focus group, female)*

Link between services / pathway

Currently, the burden of providing community/social support was placed on the NGOs or DECCs in the community. Health professionals from different disciplines suggested that a road map or pathway was necessary to guide the next steps and list out what resources were available.

> 現在這個 service 也是很偏向 piecemeal 的。即是我們做 medical，psychi 做 psychi，即是 community，有 private，即是各個有各個的做法。那 interface 不是很大的。
> 還有是 caregiver 的 training 是很重要的。你要 empower 他。
> 那麼他覺得他自已 handle 得到是會好很多的。早一點 educate 他們的。
> *(Geriatrician #1, focus group, female, Associate Consultant)*

The provisions of post-diagnostic care at the community level was again emphasized.

> 一定要配合很多事情，不只是 diagnosis 重要。What if 我 diagnosed 了他 dementia，根本你的 community 根本沒有 aftercare。只是我給他處方藥物，處方了藥物之後，我也做不了什麼. 那麼其實你 increase awareness 也是浪費力氣的… 但是回到家中, 又沒有人照料他，他又 depressed。他 depressed 了，又不服藥。那麼是一個循環來的，是一個 loop。*(Geriatrician #1, focus group, female, Associate Consultant)*

> 我想現在缺乏的, 就是在community沒有一個統籌, 或是一個大的地圖, 是一個pathway。即是我們去到哪一個step，是可以拿到什麼resources而希望政府花錢下去的時候，是好像剛剛那個同事也說，也是problem focus了。*(Private PCP #2, focus group, male)*

Different concerns were raised by the professionals, including the need for a centralized scheme/list to facilitate PCPs referring community services for patients, the gaps and connection from one type/round of service to another, a one-stop webpage for patients/caregivers to navigate and look for relevant services, and the projection of service needs for dementia in the long run.

> 如果可以的話，是應該可以有一個 list，我們自已可以 at hand，即是很輕易 refer 病人去做 assessment 也好，去做 day centre 也好，即是做一些 cognitive stimulation 的事也好，而且會給一些 pamphlets 給 family 看看。*(Private PCP #3, focus group, male)*

> 正正就是由一個服務到另一個服務，可能這個服務停了之後呢，其實可能有個斷層。

> 他們就會不知道怎麼辦，即是自己怎樣呢？其實我在這個階段，究竟要怎樣呢？其實好缺乏有個 case management 的 system 去跟進他們，有時他們脫離了某一個服務，那些就是不知道怎麼辦，又或者如何進入，也是一個困難。*(OT #2, focus group, female)*

> 那麼會不會有一些webpage可以是在中間點，而big wish可以是做得闊一點，which他們可以在網上一站式，去到就已經是可以找到我十八區，我找到我自已那區有什麼服務，或是我DECC是什麼，最好找哪一個姑娘負責，因為很多時老友記入到DECC不懂說，他們很想，但是也未必懂得說自已有什麼問題，也不懂得說自已有什麼需要。
>
> 還有是分配那個先後緩急，而且我覺得early是應該可以多做一點的，因為除了DCSS這一類服務，如果是服務early [diagnosed]，你是可以provide到那個carer education讓他知道整條路是怎樣走，去到哪一個stand point你遇到什麼，你便找什麼，那麼我覺得其實是他們是最驚，當我有問題的時候，我不懂得找，但是如果他手上已經有這個map，這個普模的時候，which 哪種東西是user friendly，在我附近，我相信這個心理的support，便會好很多。*(OT #1, focus group, female)*

> 反而我是想說，你問我如果是要投放資源下來，我覺得是需要做好那個規劃，其實plot到整條線，究竟dementia是應該怎樣去更新，或是怎樣去guide入面的人口，到底有多少人口到底有這些病，其實是可以plot到整個路線圖。
> 但是你問我，我會見到他們那一個規劃是頭痛醫頭，腳痛醫腳。*(Social worker #1, focus group, female)*

III. Dementia Community Support Scheme (DCSS) – Views of caregivers and healthcare professionals

3.1 Scope and eligibility

Healthcare professionals and service users of the DCSS all agreed that the Scheme provided comprehensive post-diagnostic care including continuous assessment for patients and their caregivers within the provision period. The main concerns expressed by the stakeholders were the coverage and eligibility of the Scheme, that is, who could benefit from the services and who could refer patients to the Scheme. Specialists pointed out that DCSS could only tackle mild dementia cases with little or no behavioural and psychological symptoms of dementia (BPSD).

> 但是moderate 到 severe 的那一批，現在也是 deal with 不到的。即是我們 refer差一點 [case] 給他 [DCSS]，他也真的很直接反彈……是啊。DECC 那些，他們也說 tackle 不到。因為他們的 centre，他們的 manpower，即是有一個 limitation 的，即是如果那一

> 個去那個 day centre 那方面搞破壞的，也是沒有這麼多 staff 看著他。是不是？
> *(Geriatrician #1, focus group, female, Associate Consultant)*

The same concern was shared by PCPs and social workers who thought the bulk of dementia patients who were in dire need could not benefit from DCSS which had a limited capacity.

> 我常常說入到智友醫社的那一個組群，其實是得到很大的祝福。在社區裡最大批的組群，其實是未入到DCSS那群人。因為你試想一下，可能每年DECC只有五十個病症(配額)，但是在社區裏面當然是不只這個數，反而正正我們常常也說智友醫社已經是有一群專業團隊去看他，其實那一群朋友我們不太擔心，honestly。
> 是未入到這一個組群的朋友，其實是我們最需要再放多一點資源去support，…反而我們常常說最需要關顧的人未入到DCSS那一個組群，這一個組群有的壓力才是更大。
> *(Social worker #1, focus group, female)*

> 其實很視乎那個scope是做什麼的，可能他是想……即是很多時，那個programme是在dementia management裡面弄一個五星級服務的樣子，但是可能服務一堆人，即是可能是selected的case的樣子，我不知道他的capacity可以做到哪樣。
> 是啊。但是例如他們那個output是可以care到多少人，是不是在一team人之中care到多少人的樣子。我不知道。*(Public PCP #2, focus group, male)*

3.2 Quota not filled up

Despite its limited capacity, it was pointed out that in some districts, the 50-quota for DCSS was not filled up. The reasons for such varied: accessibility of the training venues, impact of the Covid-19 situation which deterred people from going out, lack of knowledge about community resources, exclusive source of referral which made only attenders of geriatric and psycho-geriatric clinics eligible, and geographical boundaries.

> 是啊。真的是有位剩。因為在疫情影響下，他[patient]可能是未必下來的。在未有疫情之前，其實有一些位，其實也是不知為什麼不夠數的，下來不到的。
> 我曾經聽過有一些中心可能只有兩、三個cases，也是有的。即是那段時間。我覺得會不會大家也知道其實社區資源其實有多少呢? *(Nurse #1, focus group, female, DECC)*

> 在一些區，⋯有一些中心是比較difficult to get to。即是要坐很久巴士，過了一座山，才可以去到那個中心。*(Geriatrician #4, focus group, female, Consultant)*

> 如剛剛所說，好像是我們有兩間指定醫院的，老人科又或是精神科，其實他[patient]確診，也是不知道有智友醫社，可能就是我們⋯⋯致電過來，也是會有一點tips啦，說你會

> 不會考慮轉過去這個部門啊，這樣你才有機會過來智友醫社的，這樣變相可能資源其實也是有的，是要搜集回來，即是東拼西拼的感覺，有一點是。*(Social worker #3, focus group, female, DECC)*

> 是。現在是只有那兩處，所以是，好似姑娘所說，我們[這區]其實是有很多是在健康院看的，或許是什麼，其實也是入不到(DCSS)來的。是要我們跟他說你可不可以回到醫院再覆診，但是再覆診的期間，又要排期啊，所以有時就會是很長啊。*(Nurse #1, focus group, female, DECC)*

> 其實雖然，即是好多社區地方，就是identify那些人出來啦，但是他們要排服務的過程，要取得diagnosis的，其實真的是非常之漫長。可能等上幾年也未等上，還有DCSS那些呢，通常呢，就會是geri或者psychogeri，他有看這些呢才可以……即是可以refer啦，那麼在其他層面，也很難refer。 *(OT #2, focus group, female)*

> 其實是有很多dementia cases running around in medical wards, because it's just not be seen by geriatricians。So whether the medical doctor，即是那個醫生，即是可能是看diabetes，他 (patient) 也是有dementia。但是他們會不會「叮一叮」，記得我處理insulin的時間，也是要想想他 (patient) 是有dementia，我也是要refer他到DCSS的。
> So病人是在的，只是主要是哪一個去screen的，去pick up他們。*(Geriatrician #4, focus group, female, Consultant)*

Regarding the issue of from 'whom' or 'where' the patients could be referred to join the DCSS, different professionals had highlighted the present constraints and some suggested flexibility in actual operation, including going beyond geographical boundaries and providing support, assessment and information for walk-ins at DECC level.

> 那家醫院是沒有DCSS，但我們還是給他們refer，將來我還是會給family medicine refer to我們，因為我的目標是想serve整個cluster的dementia patients，我是不會constrained by 我的geographical，又或是departmental constraints。
> 所以是要看看那個區的那個coordinator是想怎樣，用多闊[scope]去serve那個病人，即是you can break all the boundaries。*(Geriatrician #4, focus group, female, Consultant)*

> 還有，有時候，真的walk in當中，也是有一些cases，又或是他們自已中心的也是遇到一些case，懷疑或疑似的時候，其實DCSS的staff同事也是可以幫忙去支援也好，或是給意見也好，或是做評估也好。各方面也是…這個也是可以的。即是可以做到的，即是變得……不用光是靠醫院那邊的referral。因為其實有時候有些cases，真的根本未去到看geri又或是psychigeri，這一群是絕對有的。*(Nurse #4, focus group, female)*

3.3 The middle person

The DCSS, as a HA model of medical-social collaboration, had designated a senior nurse (APN) whom they considered suitable to be the link/coordinator among the different disciplines, or as the connection point/ middle person between the medical and social.

> 我們會有一個…APN同事，who is going to coordinate the management by these DECCs and then the connection with HA doctors。
> In fact, yesterday，我剛剛開了一個case conference，with他們[NGOs]，例如他們有什麼問題，那麼他們找我呢，其實我有一個護士去幫我做這些事。
> 但是你可以想像在一個private GP的setting，你是不會有這個middle person去做這些事，那麼病人有dementia may not have navigated to the next person.
> 之後，還有一個問題是什麼，例如是這個nurse 也是可以帶很多medical information下去給DECCs。*(Geriatrician #4, focus group, female, consultant)*

Participants, especially among the nurses, agreed that the APN did provide a channel for faster communication between doctors and patients under the Scheme.

> 那麼其實也是很依靠，即時跟APN去溝通、去了解啦。那麼，而他們也是就是把一個message帶回去醫生的，因為我們是接觸不了那個醫生的。
> 但是我覺得如果是跟HA那一邊，是有一個這樣的互通的時候，其實某程度上也是比以前好，真的…… *(Nurse #4, focus group, female)*

3.4 Attitude change

Moreover, it was also noted that the operation of DCSS had brought about attitude change in the DECCs, staff and workers were encouraged to pay more attention to the needs of members with dementia symptoms.

> 但是其實中心裡面，例如那個真的有這一個project的時候，也是真的提昇了社區裡面，中心裡面的人，也會留意其實有dementia的老人家……
> 即是他們可能什麼也可能反應慢一點，或是没有認知多一點，没有那麼知得清楚中心裡的活動，我覺得過程當中也是看到……慢慢慢慢，其實那個在DECC裡面，是會真的多一些關顧。*(Nurse #4, focus group, female)*

Focus of intervention was also shifted to the role and support of the caregivers as they would continue to play a major role in the daily life as well as long term care of the patients.

> 反而我們近來轉了策略，就是針對護老者。
>
> 常常也說他們來上你那個一個小時課程其實是很開心的，很歡愉的。但是只不過是他家裡的成員如果不認識病症的話，又或是不認識訓練的方式，跟他說話的模式，跟他相處的方法，跟他溝通的方法的話呢，其實他在剩餘的廿三小時，也是要家人忍受的。
>
> 反而這幾年，我們DECC改了一些策略，是主動針對照顧者的。
>
> *(Social worker #1, focus group, female)*

3.5 Collaboration within DCSS

Participants also mentioned about the need to equip themselves with regard to collaboration with different professionals, that to adapt and adjust was a must in multi-disciplinary collaboration.

> 那麼我覺得這一個是很好的合作模式。好處就是那一team人，大家受的training也是很不同。著重的事情也是很不同，那麼其實在合作方面，大家是有很多地方去傾談、解釋令到對方明白自已究竟在說什麼。
>
> 這些cases [patients] 便會有一個不同角度的…不同角度的professional人去幫助他，於是他的問題是可以得到多角度跟全面一點的幫助，這樣子。*(Nurse #3, focus group, female)*

> DCSS在DECC，其實我覺得多了一種東西就是，突然多了一些medical staff在啊。
>
> 還有，我覺得那個team當中是，也是大家在互相合作的。即是大家需要互相配合的。
>
> 即是如剛剛所說，在接觸的工作，裡面其實也是有很多個範疇。那麼我會覺得……也會是有很多需要，是需要繼續在自已training裡面的需要，即是有的。
>
> 即是不管是藥物，還是病呢，又或是即使是一些的……其實社工那一方面的skills，我也是覺得很有趣的。*(Nurse #4, focus group, female)*

Despite that, DECC worker noted the difficulty in enabling two-way communication between the medical and social sector. It seemed both parties were working on their own following their own agenda.

> 因為醫管局的架構其實就是動不了啊… 其實社有社自已做，醫院有自已醫院的運作。
>
> 你告訴我，其實叫坦白說，一個叫智友醫社，一個叫醫社合作的平台，其實我work out了，由2017年到現在，其實只不過大家有自已的運作模式，其實只不過是中間裡面，我相信是經歷了數年的磨合，在過程中大家在一些項目認識多了，但是在架構裡大家也不是怎樣移動，我的感覺是。
>
> 我覺得是NGO的彈性很大，我常常說NGO基本上也背負著一件事是就是使命必達，那麼政府落實什麼措施、什麼services，其實大家是no say的。
>
> 基本上我很記得當日只是由2017年就爭論一件事，即使是case下來，稱之為下遊。如果我們由DECC說，我有一個回轉的機制。但是這一部份，其實是在醫院裡，也是角力了很久。這扇門不是很開到。*(Social worker #1, focus group, female)*

3.6 No planning and funding for post-DCSS care

Healthcare professional participants who were involved in the DCSS expressed their concern about the aftermath of the Scheme's provisions for the dementia patients, whom after a substantial period of improvement and maintenance in their cognitive conditions, would face the challenge of deteriorations and lack of further support if there were no follow-up plan or service extensions.

> 而是那個 [dementia] trajectory是越來越差的，so therefore，那個crisis又或是討論就是post-DCSS要怎麼辦？還有去到跟他們[patients]最需要你的時間，最多carer stress的時間，就是moderate，because他們開始步入physical frail。*(Geriatrician #4, focus group, female, consultant)*

Feedback from patient participants on DCSS was not much as only two had participated in the Scheme, the others either did not join or had not heard of it. One caregiver explained that the timing was not good when they were invited, they were overwhelmed with other concerns and did not bother to find out more about the Scheme. One participant was a newcomer and had just started his training while the family of the other participant thought DCSS offered useful help to patients and respite relief to the caregiver. Both were grateful to be part of the Scheme. Another caregiver served as a volunteer of the Scheme

IV. <u>Enhancing roles of PCPs in early diagnosis and management of dementia</u>

Despite the shared views among the participants that PCPs played a rather limited role in the current dementia care scene, it was also agreed that given more support and resources, the PCPs were in a good position to facilitate early diagnosis and render effective management to patients with dementia especially in the early stages.

> 其實如果是我們不需要去依賴這麼多公營的醫院，即是如果中間是有一些真的是社區的醫生，是不是可以做到多一點的?
> 真的是我們…有一些很有心的家人，其實是很想做的，也很想多做一點。但是不知道如何。但也是明白公立醫院那個擠迫性啊。 *(Nurse #4, focus group, female, CPN)*

> 根本就是你expected MCI 也好，你dementia的patient也是會越來越多的，那麼最ideal的就是我們primary care physician 就是一個gatekeeper， anyway我們就是patient first touch、第一個接觸的人，所以如果我們screen到一些人，有dementia 又或是MCI 的話，也是最好的。因為最多機會接觸他們。*(Public PCP #6, focus group, female)*

There were thus also discussions on measures/strategies to enhance the roles of PCPs in early diagnosis and management of dementia.

4.1 Service support on diagnosing and managing dementia

Public PCPs shared that given the current provisions and constraints in GOPC, such as the limited time for each consultation, their pivotal role to treat common chronic problems (diabetes, hypertension, high cholesterol), and inexperienced junior doctors' inability to recognize dementia symptoms, they could offer little support to the multi-disciplinary approach unless more resources were directed to dementia services which had to come from management directive. Suggestion such as setting up a special session at GOPC or an 'Integrated Dementia Clinic' modelled on the existing Integrated Mental Health Clinic where patients with mental health problems were seen together by PCPs and specialists, was put forward.

> 我剛剛也是挺同意所說的其實是要specialist clinic,… 其實是要multi-disciplinary approach，有很多東西配合的。即使你說只是在GOPC減籌號，我覺得也未必行得通。即是，起碼一種東西我們CT brain是沒有的。… 那麼另外一件事就是，那麼我們怎樣校藥呢，是很視乎scores的，…現在還要看MoCA。所以又是要東西去support的。
> 我想如果真的要在primary care裡面做specialist clinic，是要專門看這些的病人。
> *(Public PCP#5, focus group, male)*

> 所以其實說得底也是錢啊，也是一個resources去到哪裡啦，所以我自己便會覺得有什麼方法去解決，就也是一些高層次，即是可能是需要一些管理層。是啊，又或是service的planner。是啊，他們是怎樣看這個services呢，如果他們覺得primary care要involve在這一件事[dementia care]，那麼自然resource便會來啊。所以我覺得也是要跟政府啦，Bureau，或者是head office 是要buy in大家那個對這事情的看法啊。
> *(Public PCP#1, focus group, female)*

For the private PCPs, lacking resources to perform tests on diagnosis, insufficient knowledge about community resources, no formal channels to connect patients/families with community support/service package, had deterred or restricted their involvement in dementia care. The example of a dementia platform which facilitated communication between NGOs and private PCPs was quoted as good practice, enabling the latter to be better informed of resources/services offered by the NGOs that could provide the needed support to the dementia patients.

> 即是NGOs其實是有很多services呢，我們GP是可以用到。但是不知道，不知道有什麼services可以用到，所以其實如果是有一個centralised的一個scheme，讓我們GP可以知道自己區內的NGO有什麼services是可以provide到，那麼是很重要的。
> 如果可以的話，是應該可以有一個list，我們自已可以at hand，即是很輕易refer病人去做assessment也好，去做day centre也好，即是做一些cognitive stimulation的事也好，而且也是給一些pamphlet給family看看。
> 因為他們曾經過來(我們區)做了一些introduction，所以我想有一些私家醫生也是這樣refer病人，但是要有一些渠道，即是不光是這個區，例如是全港的話是要有想這些渠道出來發放，我們才會知道GP是可以怎樣做。*(Private PCP #3, focus group, male)*

4.2 Incentives to look after patients with dementia

As shared by most healthcare professionals in the focus groups, there was little incentive under the present constraints for PCPs, both public and private, to engage more in dementia care. Several measures were suggested to offer incentive for PCPs to enroll in further training on dementia/community geriatrics and made it a prerequisite for looking after elder/dementia patients.

> 其實如果你，政府是想manage一些geriatric patients，不要光是說dementia。你是需要讀一個diploma course有一點認識，然後他才可以pick up到這些東西，不是一個普通GP就是讓他handle geriatric case會有一些問題出現的 … 那些GP是應該有geriatric training，就是讓他做這一件事、就是希望可以盡早幫助政府處理這些elderly patient with multiple medical problems plus dementia，我想這是很實際的。
> 你沒有incentive，讀了是這樣，不讀也是這樣。還有什麼用? *(Private PCP #4, focus group, male)*

> 但是對他來說是不是有rewarding的東西，不要想是不是功利。但是他會考試，不如考一個Fellow，如果是這樣子，那麼我無謂讀一個Diploma [in geriatrics]，即是這樣說。
> 即是如果像我這樣子，只是打工的。我不需要，做不做也是這樣子。
> *(Private PCP#5, focus group, male)*

Offered vouchers for patients to visit PCPs with community geriatrics training and undertake radiological imaging or laboratory test to facilitate early diagnosis.

> 其一，又或是最好有geriatric voucher，即是有一個Diploma就是可以用…例如看一個病人就是mobilise $3000、$5000，每年…大家是不是輕鬆很多。就是整一個order一個CT Scan, 即是可以有一點用途, 是不是可以即是這樣東西, 我的意思是這樣開始有incentive, 也是可以幫輕到一些什麼。*(Private PCP #2, focus group, male)*

4.3 Designing patients' management plan with nurses and social workers

Conduct long-term planning with patients, provide post-diagnostic care by bridging patients with community resources

> 另一個可能想法，會不會可以跟NGO合作啦，即是，是啦，因為又有合想法，即是其實他們NGO是有很多dementia programmes，是不是之前就有好多funding。
> 現在他們有support，即是有人，即是他們有nurse，[social worker]，又有OT的。那麼which is 不知道可不可以是link up with 我們的樣子，我們是有東西可以給他們的。那麼他們又有funding的。*(Public PCP #6, focus group, female)*

4.4 Enhancing support to the caregivers

The importance of caregivers in dementia care was recognised by PCP participants of our study, and it was also crucial that their needs were catered for and caregiver support was rendered. Respite service for the caregivers, sharing online cognitive training materials with the patient's families/caregivers, educating caregivers about the patients' dementia, and helping them with stress management were areas that PCPs were capable of. To do this, the PCPs needed to equip or upkeep themselves with knowledge and information on community resources and support, such as web-based training and apps.

> 有一些case真的是，他不是那個patient不是那個dementia patient來看我，而是有一些case是那個caregiver來follow-up，chronic follow-up他，變成他很depressed，然後他又覺得很困身，我便會給一些，即是唯有這樣子，唯有refer他去…建議他去SWD那裡找啊。通常也是希望、期望有一些day care centre可以幫上忙，relieve到他們。
> *(Public PCP #3, focus group, male)*

> 我也是知道有一些web-based的電腦是做一些cognitive training。例如是說剛剛說的Primary Care Framework那個module。其實我曾經按了下去，是做一些手眼協調的，即是有一些遊戲給老人家玩、去按。
> 另外有一些，其實我也很同意要由problem入手。例如曾經有一些病人fall啊，跌啊，有一些trend是parkinsonism with這個cognitive impairment，即是處理parkinson的那回事。
> 另外就是曾經走失，get lost，就是社區上也有一些apps就是給家人跟社區安裝在電話，

> 幫忙尋人也是有的。
> 我知道有這些資源，家人也是可能interested的。是啊，我會分享這些資源也是可以在GP那方面幫忙。 *(Private PCP #1, focus group, female)*

> 剛剛我又加一點在那個carer stress，其實是很多時那個dementia的病人..,但是很多時也是家裡noticed到他有問題。其實那個……carer本身，對我們來說，可能也是變成一個隱形的病人，是不是？很多時候我們要照顧那一位carer，因為你去support那個carer，如果不然，[她]如何去照顧那個病人。*(Private PCP #2, focus group, male)*

> 那這個時候，你可以幫助那個caregiver suggest給她知道，又或是advise她在這個情形，你先生有這個問題，要她很accept他。除非是不想再接受她的先生。Otherwise，她一定要很generous，一定要accept她的先生是有這些問題，你要解釋給她聽，讓她不要feel bad，因為她的先生常常說她偷他的東西。讓她感覺不是「食死貓」，讓他明白她的先生有dementia有這樣的問題。這些會幫助他們。
> 那麼那個caregiver will feel much more relaxed and easy to accept what is going to happen，那麼她可以舒服很多。那麼我們可以幫助communication between herself and the demented elderly。*(Private PCP #4, focus group, male)*

4.5 Potential role of PCPs in DCSS

Although currently PCPs did not play any role in the DCSS, instance of private PCP referring their patients with dementia symptoms to receive cognitive training and fee-charging services from NGO in the community revealed similar form of medical-social collaboration in the private sector. The problem was how affordable and sustainable it could be especially for families that had a tight budget.

> 其實我多數有case便會refer給他們 [NGO in the district that rendered paid dementia service]。…它不光是做cognitive的東西，但是似乎也是很supportive，就是除了是費用以外。是啊。這個是很重要的問題來的。因為病人的反映[feedback)是很好的，但是不知道是可以做多久。
> 所以為什麼我剛剛說diagnosed之後，除了legal其實之後的supportive，例如是socially應該如何做？如果他診斷了，做得挺好、變成很滿意，但是費用如何呢？
> *(Private PCP #5, focus group, male)*

Moreover, to ensure this would work, PCPs had to receive adequate training in making diagnosis and did not miss out relevant factors. Government support in this respect was necessary.

> 但是在我們未refer病人給這些[NGO]機構之前，我們要make sure我們不是miss了剛剛P1

> 醫生說的secondary dementia。如果…我們沒有manage到，只是直接refer到那間NGO。他們不知道的，那麼便會弄出事件來。
> 但是在這個過程，是要用很多錢的。那麼希望政府明白這回事，但是GP要稍為多用政府的錢去，screen了病人才可以幫助病人manage Alzheimer在NGO那面，如果不是，就是會有很大的事發生。*(Private PCP #4, focus group, male)*

> 但是如果真的有一個proper training on… 例如是我們diagnosis之後，例如即使我們是collaborate with specialist，去再care病人。… 我很想知道我們可以怎樣做，可以on-going survey這個病人，surveillance 如何變差。有什麼警號，有什麼支援。我覺得這件事對我們GP那個continuity of care是很重要的。 *(Private PCP #1, focus group, female)*

4.6 Prevention and monitoring reversible conditions

As patients' regular doctor, PCP participants concurred that one of their main tasks was to monitor patients' health to reduce risk for the onset and progression of dementia.

> 但是vascular dementia 我們可以幫到很多。我想這方面，我想就是一定要做，GP就是要screen for那些metabolic indexes to avoid future vascular problem，跟這個pick up reversible dementia，like depression，其他當然啦。
> 但是即是如果是跟從外國做了所有，那麼可能政府要spend一些錢給GP去做一些investigation，然後assess了。然後我會manage得到那些病人。減少，起碼減少certain large proportion of treatable dementia。*(Private PCP #4, focus group, male)*

Suggestions were also made to develop screening and monitoring scores for PCPs to facilitate their monitoring of patients' chronic conditions predisposing to the development of dementia.

> 即是可能是他[patient]回來覆診，可能我知道他是MCI，又或是mild dementia，那麼可能每一年 DM complication screening的樣子，即是每一年又做一次的score，那時候可以看到那個score的趨勢，類似一些。… 那麼我們可以早一點intervene，又或是早一些可以alert system去intervene。
> …可能這些hypertension [patients]，我們可以有一些easy detection的scores也好，什麼也好，他們來一次覆診，發覺他有一些這樣的change的時候，那麼我們可能會trigger到有一些services也好，一些referral也好，可以給他們。…即是在順便看其他東西的時候，我們中間可能的時間，一年兩年，可能有少少的screening給他，讓我們看看他的progress是怎樣，然後發覺原來真的是差了，那麼那個時候，我們便會早一點intervene。
> (*(Private PCP #2, focus group, male)*)

Preventive measure like a large scale MoCA for persons at aged 65 was also suggested, which would be useful to see how blood pressure control could help prevent dementia.

辦一個五年的project，起初是我們Day one、enroll 65歲的老人家，例如是100個的。在65歲的時候，先做一次MoCA。然後follow up五年，65歲到70歲，每一年看看他的blood pressure control好不好。如果他blood pressure control得很好，五年之後，看看他的dementia會怎樣，如果他blood pressure control得很差，亂七八糟的樣子，又怎樣。這回事是很有意思的。

五年之後，有一些很強的力量，告訴人知道我們應該怎樣怎樣，就是prevent了一大堆burden to community，這個是問題。*(Private PCP #2, focus group, male)*

DISCUSSION

Dementia care in Hong Kong, like many other chronic and common illnesses, had been specialist care-oriented, that is, geriatricians and psycho-geriatricians played a predominant role in the diagnosis and treatment of dementia patients, while other professionals offered supplementary service and support. Relying on specialist treatment was a rather unique feature of Hong Kong's healthcare system, it was therefore not uncommon for patients/families to go straight to the specialist geriatricians or psychiatrists when they first noticed memory/behavourial problems.

The major issue is, as one of the private PCPs in the focus group put it, "the ultimate problem is there are too many elderly patients and too few geriatricians". Not only will the dementia patient population grow exponentially in the coming decades, making it implausible for the specialists to take up the heavy burden of care alone, the cost of care will also be very high in the long run as dementia is a chronic and declining illness. Not many patients will be able to afford the long-term costs of care without government and community support. Moreover, as emphasized above, to tackle the challenge of a growing dementia population, early diagnosis and treatment is the key and that requires a strong and accessible force of primary care professionals and service network to support it.

As revealed by our participants, currently a large proportion of services for dementia patients are diagnosis-oriented, that is, one needs to have a formal diagnosis of dementia to be eligible for most hospital and community government-subvented services. The waiting time for cognitive assessment by public specialists ranges from 2 to 8 weeks for acute and severe cases, and to more than a year for other cases, which implies early diagnosis would not be too early if the patients lack alternative resources but have to queue for public care. This renders interim measures during pre-diagnosis stage more significant and essential to prevent deterioration of the dementia condition. Moreover, patients' preference to treat other medical problems first until BPSD symptoms emerged which they and their families were unable to manage had also caused delay in their help-seeking. To promote awareness of the nature and trajectory of dementia and its impact on the families through public education, and the advocacy of primary care services for dementia and enhancement of caregiver support are important steps that require greater urgency and priority.

The role of PCPs was much discussed during the interviews. Despite the unimpressed responses from the patients/caregiver participants towards PCPs' contribution to their care experiences, most healthcare professionals agreed that PCPs could take up more apart from making referrals and prescribing anti-dementia medications. The important point is, they need back-up in order to overcome the hurdles and constraints that limited their role to conduct diagnosis and render pre and post-diagnostic care to the patients. Without the required resources and training, it would be difficult for them to fulfil their expected roles. Government involvements, in terms of policy measures and tangible support for incentives and training provisions, are necessary in this respect.

With regard to medical-social collaboration for dementia care in Hong Kong, PCPs might not be a suitable candidate serving as the middle person between the medical and social sector. The time constraint felt by PCPs at GOPC for each patient consultation left them little room to perform coordination work, not to mention about connecting patients with community resources, while the PCPs in the private sector, had no formal structures and information channels that facilitated their role as a middle person. Nonetheless, they could certainly share the burden of conducting assessment and diagnosis with the specialists, help manage treatable causes predisposing to the development of dementia, render advice and support to the caregivers as well as working with the other healthcare professionals. The suggestions to strengthen collaboration between psycho/geriatricians and PCPs working in the same district, the adoption of a co-care model, mini-joint clinic based on the GOPC PPP Programme, or Integrated dementia clinic are all viable options that build on existing structures to provide better medical and social care to dementia patients.

Our findings also showed that the role of an effective caregiver was significant especially during the pre and post-diagnosis stage. Training and supportive service for caregivers needs to run side by side with services for the patients since at the end of the day, they are the ones who spend most of the time with the patients. Currently, support and training services specially catered for dementia caregivers are offered by DECCs, NECs, and NGOs specialized in dementia care. Online information and support apps for caregivers, such as the REACH-HK II (35) – a multi-component caregiver support intervention Apps, are also readily available to caregivers who are sufficiently motivated and possess the time and abilities to seek support for themselves and their demented family members. What needs to be emphasized are the needs of those caregivers with less resources and greater financial constraints. How to connect them with available resources and/or provide handy support to lessen their care burden require practical measures and initiatives to be installed.

The provision of day care centre service provides the needed cognitive training and care for the patients and good respite for the caregivers. For the majority of families, community care vouchers, presently offered to those on the waiting list of home/hostel placement, provide useful support to patients to benefit from day care services, the demand of which would certainly expand. Moreover, measures to cover expenses on doing cognitive assessment in the private sector or at primary care settings, and extend eligibility to benefit patients who choose to stay living at home should also be considered.

Participants expressed their concerns about the piecemeal nature of the different provisions and services, individual efforts without integration and coordination and variations among different clusters. It was worried that the benefits of early diagnosis would be wasted and cause adverse effects if post-diagnostic care or community support service were insufficient and uncoordinated. The need to have long term projections and planning is pressing given the rapid ageing of the society and the growing population of dementia patients. At the NGO level, the effort to establish a one-stop service/model which includes primary care services, specialist assessment, day care and hostel placement, training activities for patients and caregivers plus research and development activities are fruitful despite operation costs and user affordability being the major limitations. It was because of the same reasons that our participants who had employed private services had to return to public care after a short period of time.

The many strategies discussed in our Study highlighted the effort and importance to build a medical-social platform where different healthcare professionals could effectively communicate and exchange. DCSS was an initiative that responded to such demand. Our findings revealed several areas for improvement. While an enlarged capacity (a quota of 50 for each district at present) could enable more patients/families to benefit from the Scheme, the incident of under-use at certain districts suggested the need to increase the source of referrals and greater flexibility in operation. To allow PCPs and NGOs to make direct referrals to DCSS facilitates patients' accessibility to the Scheme as well as other primary care services and community support.

Apart from having medical-social platform at the hospital level, a similar platform to be set up at the district/community level would also be worth consideration. As lack of knowledge and information about dementia care and community support services was quoted as a major barrier among our patient and PCP participants, the platform could help facilitate the transmission of useful information which will not only be useful to DCSS participants but also to the wider public with similar needs.

NGO/ DECC are the main providers for community support to the dementia patients and their families. The growing demand has also exerted pressure on them and more resources to be assigned to them are inevitable. The need for nurse and allied health professionals to have continued training in dementia care is also an important point to note. Furthermore, post-DCSS planning and provisions, although not directly related to early diagnosis and management, are areas that need to be taken into perspective given dementia care is a long term battle.

Limitations of the study

This qualitative study had several limitations. First, owing to the Covid-19 situation, most of the discussions and interviews were conducted online and/or over the phone, interaction among the participants and between the interviewer and interviewees might have been weakened. Yet, same techniques as in face-to-face interviews were applied to facilitate expression and exchange of opinions and experiences. Second, the recruitment of participants, especially patients and caregivers were restricted by the cognitive state and abilities of the patients. Their views in some cases were not clearly conveyed due to their declined memory, in other cases where both patients and caregivers were present, the patients' descriptions were able to be supplemented by their caregivers. Third, the sample of caregivers were exclusively female in our Study which might to a great extent reflect the real situation, the views of male caregivers were not included in the findings.

POLICY IMPLICATIONS AND RECOMMENDATIONS

Based on the research findings, we suggest the following strategies to enable optimal use of resources by primary care providers to enhance early diagnosis and management of dementia:

1) Public education to raise awareness about early diagnosis and management

Despite the increased public awareness to dementia as an illness in recently years, the notion of early diagnosis and management has not received its needed attention when compared to other chronic illnesses among the general population, especially the older people. Systematic measures and publicity campaigns that emphasise seeking help from PCPs and NGOs in the neighbourhood which render elderly health care and services with memory problems and impairment will be useful to raise awareness. An '*Early Diagnosis Programme*' in the form of free or subsidized cognitive assessment conducted by private PCPs would motivate and facilitate the public to seek primary care help for their cognitive and mental health. The campaign/programme can also convey the important message that dementia can be taken care of at the primary care level, by family doctors with good community support. Moreover, public education with themes on the prevention of dementia onset and progress by linking it with good maintenance of the '3-highs' (diabetes, hypertension, and hyperlipidemia) can also be emphasised.

2) Subsidise continued and further training in dementia care for PCPs

The advocacy of early diagnosis and management requires tangible support both in manpower and resources. Further training on dementia for PCPs organised by NGOs, medical associations, agency specialized in dementia services and tertiary institutions (36) had proved successful in fostering a strong team of primary care force and share the burden of care with psycho/geriatric specialists. Government involvement and funding support or reimbursement policy for higher training in community geriatrics and dementia care will serve as incentives to encourage more PCPs to join the force.

3) Enhanced care for the caregivers

To enhance the bio-social well-being of caregivers should be one of the key components in primary care services for dementia patients as caregivers are significant stakeholders in the care paradigm. Apart from the rich pool of caregiver supportive programmes and training activities rendered by DECCs, NECs, NGOs, respite and outreaching services to caregivers with greater care burden and constraints should be designed and financially aided. PCPs can also provide biopsychosocial treatments for caregivers during their medical consultations. Online apps and training materials which provide greater flexibility and applicability are also good resources for the younger caregivers.

4) Expand Public-Private Partnership Prgoramme (PPP) to include dementia treatment

This is a provision to enable dementia patients who have been diagnosed at the SOPD and whose conditions are stable to be followed up and managed by primary care physicians with geriatric/dementia training in the community. It helps enhance patient access to primary care services as well as provide choice for patients to receive care from the private sector, and also helps shorten the waiting time for dementia care at the SOPD.

5) Set up Mini-joint Clinic at GOPC

A co-care model where PCPs at GOPC can work together with Psycho/geriatricians to treat patients with dementia symptoms. This will enhance the chance of patients to have early diagnosis of their memory problems and reduce the need and waiting time for referral. Based on the current mini-joint clinic model, special sessions at the GOPC will be allocated for joint consultation by PCPs and psycho/geriatricians.

6) Expand community care voucher usage to include assessment services

Presently, people on the waiting list of hostel/residential home placements are eligible to receive community care vouchers which provide cash support for diagnosed dementia patients to employ day care services from designated NGOs. To enhance early diagnosis and management, both pre and post-diagnostic support are essential. The present voucher provision only covers patients who are diagnosed and waiting for residential placement, it would be of great help if the provision can be extended for patients who choose to visit PCPs with community geriatrics training and undertake radiological imaging or laboratory test for early diagnosis, and those who prefer to continue staying at home but also able to receive day care services in the community.

7) Enable different sources of referral for DCSS

To ensure smooth and efficient operation of DCSS, there is the need to revise the referral mechanism and enable PCPs and NGOs involved in dementia care to make direct referrals to DCSS. By allocating certain quota to PCP or NGO referral, it helps facilitate patients' accessibility to the Scheme as well as other primary care services and community support. Moreover, it also adds flexibility to its operation and prevent resources to be wasted.

8) Establish mechanism to facilitate two-way communication between medical and social sectors

Despite the importance ascribed to collaboration between the medical and social sector in dementia care, the long-time structural arrangements and local culture have fostered a strong medical authority that presides over the healthcare sectors. To enhance medical-social collaboration, two-way or multiple-way communications among different parties are essential. The setting up of a medical-social platform at the district level with formal structures and mechanism for exchange and communication among the different healthcare professionals should be considered.

9) Long term projection and route map

Current figures and information on the number of dementia patients, their projected demands and trends in its prevalence and mortality in Hong Kong are lacking. There is little updated information about the local dementia picture both currently and in the near future. While early diagnosis and management will help reduce long term care cost and burden, to have actual figures and accurate projection is equally important. Moreover, it is worthy to explore the need for a mass screening programme among the 65+ group similar to that of a cancer screening programme. The data and results collected will be useful for long term projection and the drawing of a route map that links up the variety of service packages and provisions for dementia care. Funding support for research activities and service innovation in dementia continues to play an important part.

PUBLIC DISSEMINATION

Findings of the Study will be published in both international and local journals in the fields of geriatric mental health, dementia studies, and health promotion for the elders.

A report highlighted interesting and impactful findings of the study will be conveyed to the media. Seminars will be organized by the research team to target healthcare professionals and caregivers of elderly patients.

CONCLUSIONS

The current study provided more information on the patients and caregivers' barriers and enablers to seeking treatment and support services for dementia in the primary care setting. Apart from patients' resistance to recognise their symptoms, insufficient knowledge/ information about available community support/services and low priority given to treating dementia, which could be remedied with good caregiver support and more effective publicity strategies and public education to raise awareness, the perceptions that PCPs were incapable of treating the disease and local elderly centres were not the place for treatment had significantly dissuaded patients and caregivers from seeking help at primary care settings.

The roles of PCPs to deliver dementia care and support patients and their families throughout the entire dementia trajectory, which if performed as advocated, could help lower the burden of specialist services in diagnosing and managing dementia patients, monitor treatable causes, offer compensation techniques to train patients, support to caregivers to prevent emotional stress and breakdown, and maintain physical and mental health. However, all these hinges on the readiness of the PCPs to engage themselves in looking after dementia patients, as well as recognition from other healthcare professionals and service users. Government policy and provisions to support continued and further training in dementia care for the PCPs is the key.

The costs of dementia care, both short and long term, had also created much burden on the families with dementia patients. Government support in terms of care vouchers would be helpful, not only for day care service, but also need to include cost for assessment, and benefit users who prefer to stay home instead of queueing for residential placement. DCSS and DECCs' contribution to provide timely help and continuous assessment and support to the dementia patients through medical-social collaboration are also worthy of greater investment and development. Mechanisms to ensure greater participation of primary care providers in dementia care include efforts at various levels: continued training for PCPs, nurses, social workers and OTs as well as caregivers who would shoulder most of the caring responsibilities in both short and long term; joint effort in the form of public and private partnership scheme and specialists and PCPs joint clinic; provisions for PCPs and DECCs to make direct referrals to DCSS; and setting up of medical-social platform at district level to enhance communication among hospitals, PCPs and local NGOs.

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