

# Caregivers' informational needs on dementia and dementia care

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## ABSTRACT

**Objectives.** This study set out to examine the perceived knowledge level of dementia caregivers and the related support services available to them. The means that family caregivers of dementia patients used to obtain relevant information, their informational needs and the difficulties they encountered in this respect were also explored.

**Methods.** We recruited 144 respondents from three non-governmental organisations, and collected data using a structured questionnaire distributed in person and via postal mail.

**Results.** A typical caregiver was a daughter in late adulthood with a secondary education. Adult children formed the largest group of caregivers. More than half of all family caregivers knew about dementia, but their knowledge about corresponding aspects of care or available support services was not extensive. We found informational pamphlets and the media to be useful means of disseminating information. In general, family caregivers expressed the need to learn how to care for their relative suffering from dementia. The respondents revealed a lack of knowledge about services available in the community, which could be one of the reasons for their low levels of utilisation.

**Conclusion.** Informational needs deserving better attention by health services planners and providers alike were identified. Making services more accessible to caregivers is necessary, as they may not be adept at retrieving the necessary information.

**Key words:** Caregivers; Dementia; Family; Information services

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## INTRODUCTION

The prevalence of dementia increases dramatically with advancing age. In some overseas communities, it is reported to be around 2 to 10% at the age of 65 years, depending on the diagnostic criteria being used.<sup>1,2</sup> The prevalence doubles every 5 years after the age of 65 years,<sup>3</sup> and is estimated to be higher than 20% among persons older than 80 years<sup>4</sup> and 30% in those aged 85 years or more.<sup>1</sup> At the end of 2006, 12.6% of the Hong Kong population was aged 65 years or over.<sup>5</sup> The Hong Kong Census and Statistics Department estimated that by 2033 this group would represent 27% of the total population.<sup>6</sup> Hong Kong has nearly 60 000 older people with dementia, with more than 18 000 new cases accumulating every

year. By 2020, the corresponding numbers are likely to rise to 109 000 and 33 000, respectively.<sup>7</sup> Similar to other ageing societies, Hong Kong needs to make provisions for the increasing number of older persons with dementia. As most individuals with dementia are cared for in the community,<sup>8,9</sup> it is important to meet the informational needs of family caregivers to better enable them to care for their affected loved ones.

In both community-based studies and in hospital settings, health professionals have repeatedly under-recognised dementia cases by 20% or more.<sup>10</sup> Although the prevalence of dementia in ageing societies warrants attention, to date, improvements in early diagnosis are not forthcoming. Under-recognition of and under-responsiveness to dementia

appear widespread in general medical practice.<sup>11</sup> It is important for professionals to identify patients with dementia, and even more so for families to detect early symptoms and seek professional help. Family caregivers are often the gatekeepers and decision-makers utilising such health care services. To promote early detection of dementia and subsequent help-seeking behaviours by family members, we examined family caregivers' knowledge level and informational needs of dementia care.

Many family caregivers choose to care for their demented relatives at home for as long as they can.<sup>12-14</sup> Consequently, they are often overwhelmed by challenges.<sup>15</sup> They assume the primary role in managing, coordinating, and providing the necessary hands-on services. For instance, trying to protect their demented relatives from injury due to falls, ingesting dangerous substances, leaving home and getting lost, injuring themselves or others from sharp objects, or burns, and their inability to cope with crises.<sup>16</sup> Moreover, family caregivers also need to manage their demented relative's behavioural and psychological symptoms, including delusions, depression, pacing, screaming, physical or verbal aggression.<sup>17-19</sup> Empirical studies show that family caregivers frequently feel incompetent, frustrated, and stressed when handling such behaviours.<sup>20,21</sup>

Elderly caregiving is an awesome challenge for family caregivers.<sup>22</sup> Not addressing caregiving concerns properly results in premature institutionalisation,<sup>23,24</sup> caregiver depression,<sup>25</sup> and deteriorating physical health,<sup>26</sup> as well as substantial financial burdens to families and society.<sup>27</sup>

The health service sector can provide many options to address the needs of families who provide home care to their elderly relatives with dementia. Some crucial aspects of caregiving include caring for relatives during activities of daily living, and the means of managing agitated behaviours and accessing professional assistance when needed. However, knowing how to care for a relative with dementia is not all that the families should know. Families need to be aware of relevant services that can help them look after their loved ones at home for as long as possible. A longitudinal study showed that the availability of at least one additional support service delayed family caregivers' decisions to place their afflicted relatives in nursing homes.<sup>28</sup>

In the last 10 years, there has been a rapid development of dementia-related or dementia-specific services in Hong Kong (e.g. memory clinics, community psychogeriatric outreach teams, support groups, day care centres, respite services, and other forms of residential care). Both the public and private sectors provide these services, but many family caregivers are unaware of their availability and have difficulty in identifying appropriate medical and community support.<sup>9,29</sup>

### **Aims and objectives**

Until now, no systematic studies have examined the informational needs of family caregivers of dementia, particularly in Chinese societies. The care needs of people suffering from different stages of dementia in Hong Kong have been surveyed.<sup>30</sup> The issue of family caregiving was examined by focusing on the informational and educational needs of family caregivers. The specific study objectives were to (1) examine the self-perceived knowledge level about dementia and related available services for caregivers; (2) identify the means for family caregivers to obtain dementia-related information; and (3) explore family caregivers' informational needs and coping with difficulties.

## **METHODS**

### **Subjects**

The targeted sample consisted of family caregivers looking after a relative with dementia at home. We recruited potential respondents from three non-governmental organisations (NGOs) offering community services to people with dementia and their families. We distributed questionnaires in person and via the mail, instead of via the Internet, and could therefore reach those without Internet access. We completed the study in 2002.

### **Instrumentation**

To survey the informational needs of family caregivers of persons with dementia, we used a structured questionnaire composed of three parts. Part I collected demographic information on the respondents and their usual means of searching for information, including accessing the World Wide Web. Part II collected the respondents' appraisal

**TABLE 1**  
**Demographic characteristics of respondents (n=144)**

Characteristic	No. (%)
Age (years)	
≤24	12 (8)
25-44	63 (44)
45-64	55 (38)
≥65	12 (8)
NA*	2 (1)
Education level	
Primary school	24 (17)
Secondary school	63 (44)
Tertiary institution	19 (13)
University	35 (24)
NA	3 (2)
Relationship to patient	
Son/daughter	95 (66)
Spouse	19 (13)
Parent	1 (1)
Other relative	27 (19)
NA	2 (1)

\* NA denotes missing or refused to answer

of their knowledge on dementia and dementia care. We used a four-point Likert scale to rate such knowledge about dementia and dementia services; 1 meaning 'knows nothing', 2 'knows a little', 3 'knows something', and 4 'knows the subject very well'. Part III was specially designed to collect data concerning family caregivers' caregiving experiences. It asked respondents to give information on demographic characteristics of their family member with dementia as well as the contextual characteristics of caregiving, such as the caregiving relationship, its duration, and the caregiving difficulties they encountered. We piloted the questionnaire in a focus group to test it for readability, comprehensibility, and coverage of content areas. Accordingly, we made necessary revisions before we administered the survey.

## RESULTS

Our sample had 144 family caregivers. Nearly two thirds (63%) of the respondents were female, one third (33%) were male, and five did not indicate their gender. In all 44% were aged 25 to 44 years, and 38% were aged 45 to 64 years. About 17% of all respondents had a primary education, 44% a

secondary education, and 37% either a tertiary or university education. Among them, 66% were adult children of the demented individuals, 19% were other relatives (e.g. daughters-in-law) and 13% were spouses (**TABLE 1**). The family caregivers in this sample had been taking care of a demented family member for a mean of 45 months, with a standard deviation of 38 months.

### Knowledge of dementia and dementia-related services

More than half of all family caregivers (54%) knew about dementia; knew the disease very well (8%) or knew something about it (46%). However, they were not informed about dementia services; about 22% of family caregivers knew nothing and 26% knew something about dementia-related services (**FIGS 1 and 2**).

Information pamphlets distributed by hospitals and community organisations were the most popular (69%) channel for the respondents to learn more about dementia, followed by the mass media (65%). Training workshops reached only 30% of the respondents, followed by word of mouth by relatives

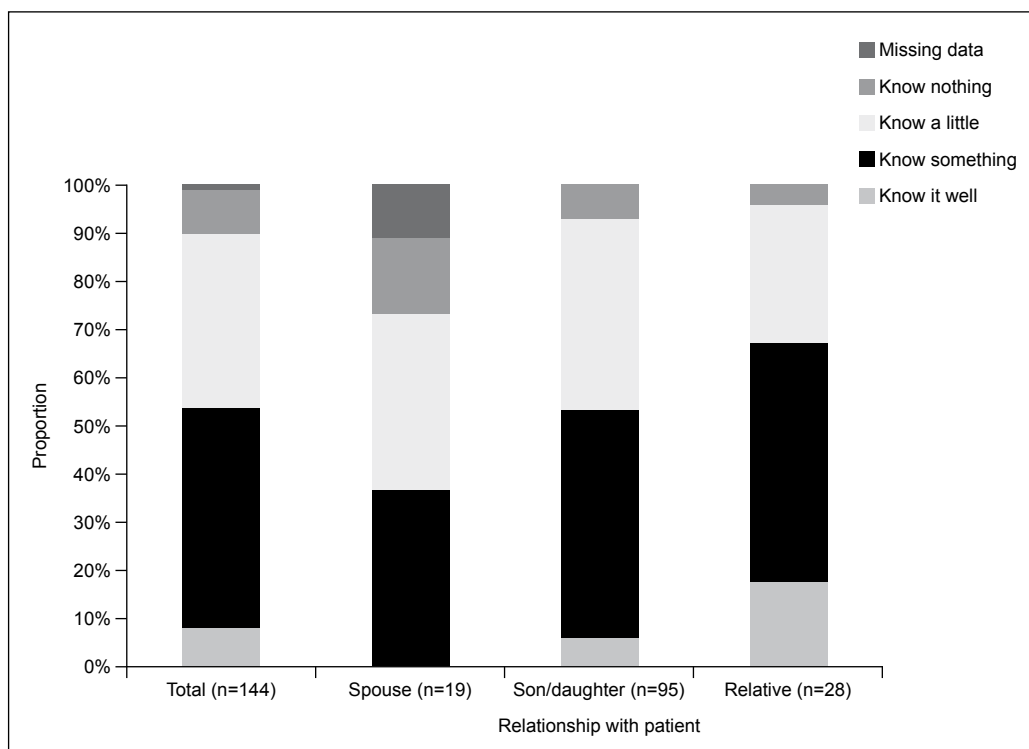


FIGURE 1. Knowledge about dementia

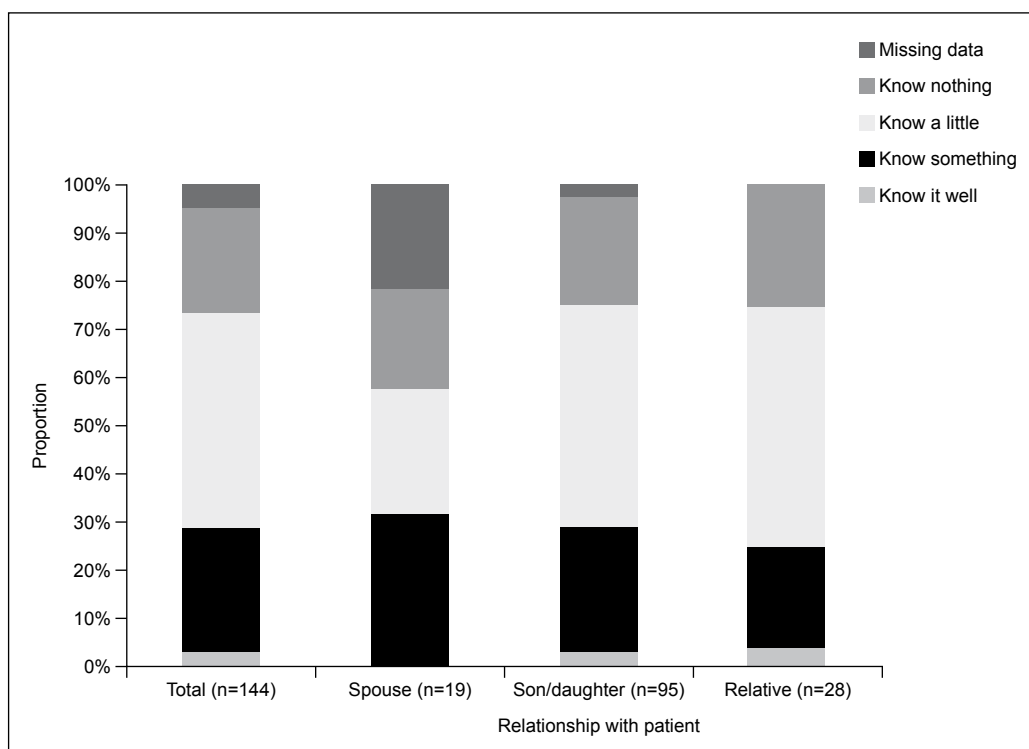


FIGURE 2. Knowledge about dementia services

or friends (16%). Visiting exhibitions or searching information from the Internet was even less popular, being used by 12% and 10% of them respectively,

though 64% were computer users, 71% owned a computer at home, and 57% were Internet users. Most respondents used the Internet to search for

**TABLE 2**  
**How caregivers were informed about dementia and dementia care**

Relationship with patient	Means <sup>a</sup>					
	Promotion article	Mass media	Talk/workshop	Relatives/friends introduction	Exhibition	Internet database
Son/daughter	69 (73%)	64 (67%)	26 (27%)	19 (20%)	12 (13%)	12 (13%)
Relative	18 (64%)	22 (79%)	10 (36%)	2 (7%)	4 (14%)	3 (11%)
Spouse	12 (63%)	8 (42%)	7 (37%)	2 (11%)	1 (5%)	-
All respondents	99 (69%)	94 (65%)	43 (30%)	23 (16%)	17 (12%)	15 (10%)

\* Respondents could choose more than one item

**TABLE 3**  
**Information on dementia care desired from Internet resources**

Relationship with patient	Type of information <sup>a</sup>								
	Latest information on treatment and care	Information of the disease	Training workshop	Relevant medical services	Relevant community support services	Application methods for services	Service category/fee	Ways to treat patient's behaviour	Open forum
Son/daughter	69 (73%)	68 (72%)	66 (69%)	66 (69%)	67 (71%)	63 (66%)	52 (55%)	48 (51%)	15 (16%)
Relative	24 (86%)	23 (82%)	20 (71%)	17 (61%)	16 (57%)	17 (61%)	17 (61%)	14 (50%)	7 (25%)
Spouse	9 (47%)	9 (47%)	9 (47%)	6 (32%)	4 (21%)	4 (21%)	7 (37%)	7 (37%)	1 (5%)
All respondents	102 (71%)	100 (69%)	95 (66%)	91 (63%)	89 (62%)	87 (60%)	76 (53%)	69 (48%)	23 (16%)

\* Respondents could choose more than one item

information (64%) and send electronic mail (TABLE 2).

### Informational needs on dementia care

When we asked respondents about the types of information they needed to facilitate their caregiving responsibilities, they responded as follows: (1) the latest information on clinical treatments for dementia (71%) and information about the disease (69%); (2) information on training workshops related to dementia care (66%); (3) relevant medical services (63%); (4) relevant community support services (62%); (5) information about service provisions such as application procedures (60%) and types and fees for services (53%); and (6) information on management strategies of problematic behaviours (48%). Two family caregivers mentioned that they would have liked a website to help recruit helpers, and two others mentioned the need for a shopping guide for products required in care (TABLE 3).

### Caregiving problems and service utilisation

Respondents could choose more than one item in their responses. The caregiving problems the

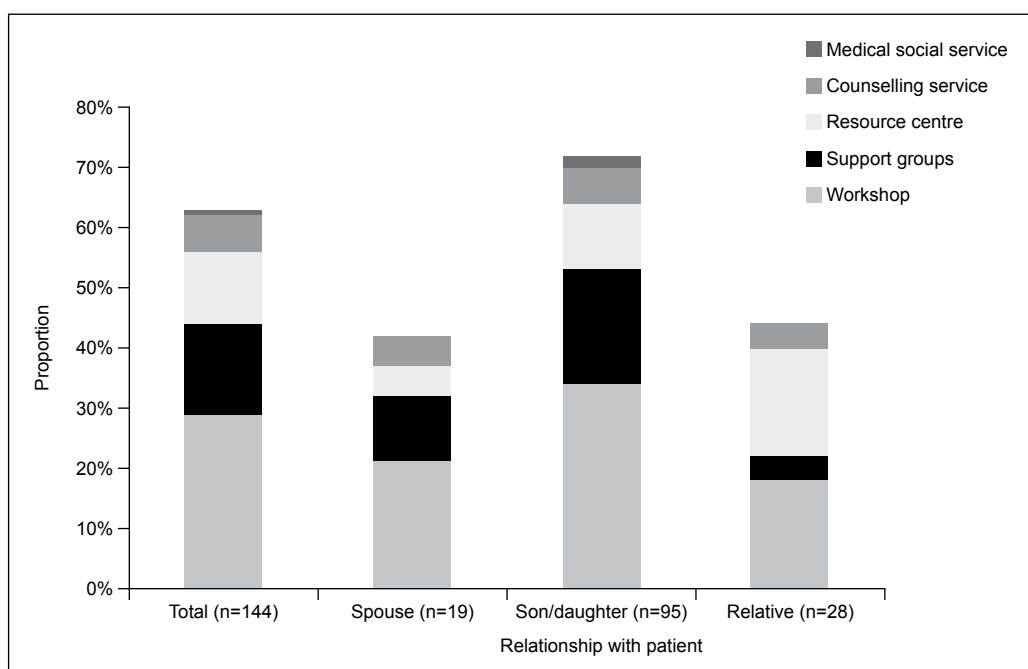
respondents encountered included inadequate caregiving techniques (48%), financial constraints (27%) and limited accessibility to service information (22%). Fifteen percent described the social and emotional aspects of caring for a relative with dementia as problematic, 13% mentioned problems associated with daily self-care activities, and 7% found the aggressive behaviours of the demented relative problematic. Nine percent of the caregivers stated that their own daily lives were affected. Six percent mentioned the long hours of caregiving each day, and 3% had problems taking care of their families when they needed to go out. Three percent found caregiving a stressful burden and 2% reported that it affected their own health. Some found it difficult to communicate with the person suffering from dementia and did not know how to express their love and concern (3%). Another 1% reported feeling worried and guilty (TABLE 4).

A total of 11% of the respondents provided information on the item labelled other problems. These included: how to negotiate with health care institutions with regard to care issues for their demented family member, how to access services, and how to request and obtain home visits by a medical

**TABLE 4**  
**Caregiving problems encountered**

Relationship with patient	Problems raised*								
	Lack of service information	How to take care of patients	Social and emotional problems	Aggressive behaviours	Activities in daily life	Caregiving duration	Worry and guilt	Affect own health and life	Money
Son/daughter	25 (26%)	51 (54%)	16 (17%)	9 (9%)	13 (14%)	6 (6%)	2 (2%)	1 (1%)	25 (26%)
Relative	4 (14%)	11 (39%)	5 (18%)	1 (4%)	6 (22%)	2 (7%)	-	-	9 (32%)
Spouse	2 (10%)	7 (37%)	-	-	-	-	-	2 (10%)	5 (26%)
All respondents	31 (22%)	69 (48%)	21 (15%)	10 (7%)	19 (13%)	8 (6%)	2 (1%)	3 (2%)	39 (27%)

\* Respondents could choose more than one item



**FIGURE 3. Service utilisation**

team. Some respondents found the attitude of health care workers as problematic; others stated that there were insufficient workers in day care centres and insufficient activities in nursing homes. They also raised concerns about the public's misunderstanding of dementia. Each of these problems was mentioned by about 1% of the respondents.

Regarding family caregivers who used community services, the most popular one they utilised was training workshops (29%), followed by support groups (15%) and resource centres (12%). Less frequently used services included: counselling (6%), recourse to NGOs (2%), and medical social services provided by the Hong Kong government (1%) [FIGURE 3].

## DISCUSSION

Hong Kong is a society where the traditional value of caregiving by extended families is still predominant.<sup>30</sup> Since most people with dementia live with relatives, we must appreciate and value these informal caregivers as a great asset.<sup>9</sup> Nonetheless, it seems that caregivers of elderly parents usually lack training in caregiving.<sup>31</sup> They receive advice from physicians, nurses, and health care providers, but have limited abilities to deliver adequate care. Not meeting the care needs of the relative suffering from dementia could be a source of stress for family caregivers, because of their perceived inability to provide adequate care.<sup>32</sup>

Most older people with dementia are looked

after by their family at home.<sup>33</sup> In Hong Kong, there is no profile for family caregivers of persons with dementia. Yet, the demographic characteristics of the study sample were similar to that described by Lai et al<sup>34</sup> on late-stage dementia. A typical caregiver of an individual with dementia is a daughter in late adulthood, with a secondary education. Children, sons and daughters, formed the largest group of caregivers, both in our series and in Lai et al's study.<sup>34</sup> Recent research has illuminated the differences between dementia caregiving and providing care to people with only physical impairment, confirming anecdotal reports that the former is more stressful.<sup>35,36</sup> Structured, time-limited educational programmes (e.g. on-site training, caregiving skills workshops) are suitable means of providing information.<sup>37</sup>

### **Matching the informational needs of caregivers**

Scott et al<sup>9</sup> identified a perceived lack of education about dementia and ways of dealing with difficult situations. When family caregivers encounter challenging behaviours exhibited by their loved ones with dementia, they do not always know how to deal with them, nor who to approach for help. Our findings are consistent with empirical studies that suggest family caregivers are in great need of information about dementia, its causes, care possibilities, and related support services, such as day care and respite services. Information about how to manage stressors, emotional issues, as well as available instrumental support, is essential to the success of family caregiving.<sup>38</sup>

Health services providers should appreciate the well-known adage that both the existing information systems and new service information programmes are not readily accessed by the less educated. We know that this phenomenon affects various types of health and social services. Since most family caregivers do not have post-secondary education, health service providers must deliver services or information to their clients in a way that they can understand. It is not appropriate for service providers to presume high educational skills among all caregivers. Rather they must provide services in a way that is accessible to those who need them most. This finding requires that service providers rethink service utilisation and service effectiveness from the perspective of recipients. Unless health care professionals or health care service providers share and make available their

knowledge, they will not be serving those who need them.

We found a large discrepancy between the services actually used by family caregivers and the range of available services provided by the government and NGOs. Accordingly, training workshops, support groups, and resource centres are the most common types of community services used by families. Whereas, only a small percentage of respondents utilised counselling, help provided by NGOs (details not mentioned by respondents) and medical social services. There are many community support services available to family caregivers, such as day care centres, respite care, and enhanced home care services. Low usage of community services may be because, either the community support services had insufficient capacity to meet demand, or the families did not know of their existence. Most respondents actually admitted that they knew nothing or very little about such available services. The results reinforce the need for health service providers to pay attention to the accessibility of the services that they offer. It cannot be cost-effective to deliver services that are known to only a few.

In reaching out to caregivers in need, the mass media was a powerful tool, whilst promotional pamphlets were also useful. Health service providers can improve their distribution strategies to ensure that information pamphlets reach a wider audience.

### **Difficulties in caregiving**

The difficulties in caregiving, as reported by local family caregivers, are similar to those reported in the literature. They entail social and emotional problems, managing activities of daily living and coping with aggressive behaviours. The respondents also reported that their caregiving affected other areas, including their own quality of life and health. Some found it a problem to take care of the relative with dementia when they needed to go out; others found caregiving a stressful burden. Some reported experiencing feelings of guilt. Local caregivers of people with dementia face the same problems that similar caregivers in other parts of the world face. Nevertheless, we need to conduct more local studies to examine how cultural differences shape dementia care.

The respondents' words, rather than the structured responses of the questionnaire, point to other areas of concern. Eleven percent checked the category "other problems", which included how to negotiate with personnel in health care facilities when discussing how to care for their demented relatives. Respondents talked about the attitudes of formal caregivers and the lack of activities in nursing homes. In questionnaire-based studies, it is uncommon for a large proportion of respondents to volunteer extra information outside of the list of structured responses. Although the percentage of respondents in these various categories was low (1% in each category of comments), they deserve attention. More than half of the issues they raised pertained to formal caregivers or service arrangements. Making assumptions based on the limited information from our respondents may be unwarranted, yet their responses indicate the difficulties that families experience when dealing with health care workers. As health care providers, we nevertheless need to reflect on our standards and the accessibility of our system, to discover what difficulties families experience, and then proceed to address these problems.

### **Making use of technological advancements to deliver information**

Moving into the realm of the cyber world may be the way of the future; 64% of family caregivers used computers and 57% the Internet. The proportions were higher among those who owned a home computer, with family members using the Internet. Sixty-seven percent of family caregivers believed that the Internet enhances public knowledge about dementia and dementia services; 78% said that they would access a website on dementia care if there was one. Conventional thinking that elderly care is high-touch and low-tech did not apply in our study, for which reason service providers need to adapt services in a way that reaches those who rely on the Internet for information. According to the Hong Kong Office of the Telecommunications Authority, local broadband Internet traffic increased from 322 570 terabits in November 2004 to 787 177 terabits in April 2007, and over a 29-month period, there was a two-fold increase in customers using broadband networks.<sup>39</sup>

Most family caregivers thought that a website on dementia should include the latest information

on treatment and care, information about the disease, and caregiving training information. They also requested relevant information on medical and community support services, guidelines on how to apply for them, and the types and costs of services available. Additionally, the website needed to contain advice on how to manage problematic behaviours caused by dementia. Whether web-based resource centre or via pamphlets, these topics reflect prevailing informational needs. Health service providers need to address these areas to help families engage in the demanding job of caregiving. As Mundt et al<sup>40</sup> contend, public education could reduce societal costs and the suffering that people experience because of a delayed diagnosis of dementia.

### **Educational needs of the care providers**

Indirectly, our findings reflect how health professionals interact with family caregivers in Hong Kong. This means that the more they know about dementia, the more they can be educated by health professionals about caregiving. Whether in Hong Kong or elsewhere, most practising health professionals and their aspiring students receive little undergraduate and/or post-graduate training in geriatrics.<sup>31</sup> In an earlier study, we discussed the importance of addressing the information needs of professional caregivers in undergraduate and continuing education programmes.<sup>41</sup> Five years since we administered our survey, we observe little change in the way institutions educate health professionals about dementia care. There may have been more continuing education activities in recent years, but health professionals still need to expand their horizons in this area. Larson et al<sup>31</sup> examined care providers' educational requirements in geriatrics, and observed that they expressed a strong need for information about dementia and Alzheimer's disease, depression, and memory loss. In the care of geriatric patients, the assessment of cognitive function and mental health status is now a priority.

### **Limitations**

As we analyse our data, we understand that our information comes from a small and non-randomised sample. We reached our respondents by means of distributing questionnaires through different individuals, including research assistants and NGO staff, surveying respondents face-to-face,

as well as collecting information through posted questionnaires. Consequently, the quality of the information collected could have been compromised. Moreover, our respondents were members of community organisations and many were already in receipt of some type of community support service. As such, our findings might not reveal informational needs of family caregivers who do not have connections to service organisations. Nonetheless, this survey was useful, given that it was the first survey of its type administered in Hong Kong. The families raised concerns that shed light on the problems that health service providers encounter within a specific framework. The findings can also help us understand the profile of the caregivers we serve and inform us of the difficulties they experience.

## CONCLUSION

This survey identifies the areas of informational needs that deserve better attention by health service planners and service providers. The findings highlight areas of dementia care and services about which family caregivers have limited knowledge. Health service providers need to make services accessible to those in need, as family caregivers may not be adept at exploring information without help. Health professionals should structure service delivery as well as promotional strategies so that service information can reach the targeted groups. Planners need to develop services and information systems that are focused and non-intimidating. Hopefully, when we develop better dementia care services in Hong Kong, we will attune them to the characteristics and needs of those we serve, rendering such services more accessible and effective.

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