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Support for family caregivers: What do service providers say about accessibility, availability and affordability of services?

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Abstract

This paper reports on a survey of providers of caregiver support services in Singapore (N=36).

The overall aim of the survey was to provide feedback to service planners and programme

staff on the delivery of services to caregivers and opportunities for improvement. A

questionnaire, comprising both closed and open-ended questions, was used to collect data.

The results showed that most health and social service providers offer counselling, case

management, caregiver assessment, financial assistance, and information. A minority provide

emergency, short-stay respite care, and daycare. About one in three provide transportation

services, which featured as a barrier to service utilization. Other barriers identified were time

commitments, lack of awareness of services, cost of care, caregivers' sense of responsibility,

lack of alternate care arrangements, and distrust. The survey also characterizes the hard-to-

reach caregivers as homebound, illiterate, socially shy and isolated, low-income and poorly

educated. Most service providers emphasize that financial support is necessary in order to

improve the prospects of family caregivers

Key words: family caregiving, formal care, caregiver support services, Singapore

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Introduction

The multiple needs and strain experienced by family caregivers are well documented in the literature on family caregiving. Research in the field of family caregiving typically focuses on caregivers and to a lesser extent, on providers of caregiver support services. It is important to research the experiences of health and social service providers as they deliver frontline services to care recipients and indirectly to caregivers. Current literature (see e.g., Feinberg & Newman, 2004; Feinberg et al., 2006; Guberman et al., 2007; Montgomery & Feinberg, 2003) suggests that most service providers have yet to recognize caregivers as a client population: they are "quasi patients", according to Weinberg et al. (2007). As a rule, service providers do not consider caregivers and care recipients together, as a dyad or family unit. One exception is in the field of hospice and palliative care, where patient and family are seen as a unit of care (National Consensus Project for Quality Palliative Care, cited in Feinberg et al. 2006). It should not be assumed that service providers are necessarily helpful; they may instead add to the stress of family caregivers if they are demanding and unresponsive (Zarit & Pearlin, cited in Lyons et al. 2000) or minimize caregivers' contributions as part of domestic responsibilities (Weinberg et al., 2007).

From the point of view of social work practice, service providers form a triad with caregivers and care recipients, and may well be the target for improvement in the delivery and coordination of services to caregivers (see Fortinsky, 2001, for a discussion of the concept of health-care triad in dementia care and the potential pitfalls of marginalizing the care recipient). In health-care research, social support has been hypothesized as promoting good health (Bowling, 2005), whether in the form of formal support (paid services provided by institutions and trained professionals) or informal support (unpaid services provided by family and friends) (Lyons & Zarit, 1999). A review of the literature shows less attention is paid to the provision of formal support for caregivers, as compared to informal support.

Literature on formal support usually focuses on the utilization of formal services by caregivers (see e.g. Gill *et al.* 1998; Roelands *et al.* 2008; Strain & Blandford, 2002) or the impact of service provider intervention on the lives of caregivers and care recipients (see e.g. Heller *et al.* 1999; McCallion *et al.* 2004). There are very few studies that focus on service providers' views or experiences (see e.g. a study by Fleming & Taylor [2006], which surveyed providers of home care services to older people in Northern Ireland).

This paper attempts to address this literature gap in reporting on a survey of providers of caregiver support services in Singapore, which was part of a bigger study on family caregiving in Singapore. In 2006, a profile study (Ng, 2008) of family caregivers in Singapore was conducted. The results of that study indicated low usage of community-based services, except for day care. The study results were presented at various network meetings of service providers, some of whom worked with older persons and some of whom specifically worked with caregivers. It was at one such meeting that the service providers observed that they could provide pertinent information on the needs of caregivers and the kind of support required to ease the strain of caregiving. The service providers were particularly concerned about caregivers' need for respite care and low usage of such services. Despite availability of respite in institutional homes, it was under used, mainly due to costs and apprehension about leaving care recipients in unfamiliar environments. Cost has been noted as a major barrier to the usage of respite care (Zarit, cited in Whittier *et al.* 2005).

Hence, the study on family caregiving in Singapore was expanded to include a survey of caregiver support services. A literature search yielded limited results on caregiver support services. However, it did identify several reports of the National Family Caregiver Support Program (NFCSP) in the United States, which is funded by the federal government and implemented at the state level, to support the needs of family caregivers of older persons. The NFCSP classifies caregiver services according to five categories: information about available

services; assistance in gaining access to services; individual counselling, support groups, and caregiver training; respite care; and supplemental services to complement care provided by caregivers (e.g. home modifications and assistive devices). Feinberg *et al.* (2005) identified respite care as one of the top ten caregiver support services provided by NFCSP. In contrast, a report by Whittier *et al.* (2005), which examined the resources provided by 33 area agencies on aging in California, "a state whose programs represent a best practice in caregiver support" (p. 48) maintained that respite service was one of the most common service gaps. Other gaps included culturally and linguistically appropriate services, transportation, financial aid, and care in rural areas. Instead of identifying types of services and gaps, Feinberg *et al.* (2006) highlighted instead emerging trends in the area of caregiver support: systematic assessment of caregivers' needs in home and community-based services; consumer choice and control in managing services, for both caregivers and care recipients; and active involvement of family physicians and primary health-care practitioners in helping individuals to identify themselves as family caregivers and to seek help, before they experience the ill effects of caregiving.

Unlike the American studies, which focuses on caregiver service providers in elder care, this study covers caregivers of children, adults, and older persons. One reason is the cross-cutting issues faced by family caregivers, whether they care for a child with physical disabilities, an adult with a mental health diagnosis, or an older person with dementia or other health condition. Biegel and Schulz (1999) suggested that it is important to separate the disease-specific aspect of caregiving from the general aspects. From a public policy perspective, the general aspects of caregiving can be addressed collectively. For example, in Singapore, families with children aged 12 years or younger and persons aged 65 or older are allowed a reduced rate on the levy for foreign domestic workers. The needs of different client groups can be dealt with through specific programmes or practices, caregiver training, for

example, would differ according to the typical health conditions of recipients. Another reason is that the service focus on family caregivers, as a target client group, is relatively new in Singapore. Since the number of caregiver service providers is small, one survey rather than separate surveys would be more cost-effective and result in a more complete sample.

The overall aim of the survey was to provide feedback to service planners and programme staff on service delivery and areas for improvement. The specific objectives of the survey were:

- (i) to document the type of services provided by community-based and institution-based organizations for family caregivers of older persons and persons with a disability;
- (ii) to identify challenges and opportunities associated with providing services to family caregivers, including funding and hard-to-reach target groups of caregivers; and
- (iii) to identify overlaps and gaps in services for caregivers.

Method

The survey questionnaire, developed specifically for this study, comprised two major parts. In the first part, service providers were asked to provide basic background and contact information. In the second part, they were asked about services that were specifically targeted at family caregivers of persons with mental illness, physical or intellectual disabilities, or health conditions such as dementias, stroke, cancer, heart disease, HIV/Aids, etc. The five-page questionnaire contained both closed and open-ended questions. At a meeting in August 2006, feedback was solicited from representatives of three key national- and community-level agencies. The revised questionnaire was pilot tested with two service providers. Exemptions from full and expedited reviews by the National University of Singapore Institutional Review Board were granted as respondents were deemed to be non-vulnerable research subjects and no risks to subjects were anticipated.

The survey was conducted between April and June 2007. Invitations to participate were sent to 51 agencies known to provide caregiver support services. The list was compiled from various sources (network meetings, websites, and agency contacts) and checked by a representative of the National Council of Social Service (a coordinating body for nongovernment organizations) to ensure coverage of all known service providers. Respondents were given a choice of various means to complete the questionnaire. Most chose to return a hard copy by post (n=24), a few chose email (n=8), and only 4 opted for a telephone interview. Thirty-six agencies responded, yielding a response rate of 70.5%.

The service providers that responded can be categorized as non-profit (n=27), private for-profit (n=8), and public agency (n=1). The private for-profit providers included six hospitals and two national-level health centres that cater to specific diseases. The health conditions addressed by the sample varied widely and included dementias/Alzheimer's disease, autism, cancer, physical handicaps, mental illness, heart disease, developmental disability, frailty. The majority (n=14) served all age groups, followed by those that served only those aged 55 and above (n=9) and those that served only those aged 18 and above (n=8). A few (n=4) served those younger than 18.

The respondents included a mix of executives and direct service staff: top management (e.g. Chief Executive Officer, Executive Director, Medical Director) (n=16); programme staff (e.g. social workers, care coordinators, nurses) (n=14); and junior executives (n=4) (with a missing value of n=2).

The analysis of quantitative data, using SPSS version 14.0, generated only frequency distributions. Chi-square and other analyses were not performed due to the small sample.

Thematic analyses were performed on qualitative data. Coding, based on recurring themes, was undertaken.

Results

The survey results are reported below, in accordance with the survey objectives. There are two parts to this section: (i) type and delivery of services; and (ii) challenges and opportunities associated with service provision, as well as the overlaps and gaps in services.

Types of Services and their Delivery

For this study, the types of services provided were categorized as follows (i) information, (ii) respite, (iii) supplementary, and (iv) direct assistance. As shown in Table 1, most agencies provided information services in the form of caregiving literature (69%) or telephone helplines (56%). Few agencies provided out-of-home respite services, such as emergency/overnight stay (10%), short-stay in institutions (25%), and day care (32%). Slightly more than half provided home support (e.g. home help, home nursing). Among the supplementary services provided, financial assistance was offered by a majority (73%), while meal delivery (16%) and transportation (34%) were provided by some.

Direct assistance refers to services that are provided for caregivers rather than care recipients. Most service providers offered counselling (83%), case management (81%), and caregiver assessment (69%). For caregiver training, more offered training that was conducted on agency premises (67%) in contrast to training that was conducted in caregivers' homes (44%). Less than half of the providers had established support groups (47%) and only a quarter of the providers offered spiritual care.

Table 1 about here

Survey respondents were asked to indicate the professions of the staff who provided direct services. The results (see Table 2) showed variations in the provision of direct assistance by professions. For the provision of health and wellness services, providers

deployed physiotherapists/occupational therapists (19%) and nurses (17%), more than social workers (11%). For spiritual care, providers chose social workers (17%) and those involved in pastoral care (14%). For home-based caregiver training, more nurses (36%) and physiotherapists/occupational therapists (25%) were involved, rather than social workers (17%). For centre-based caregiver training, slightly more nurses (39%) than physiotherapists/occupational therapists (33%) and social workers (31%) were involved. In the provision of support group service, social workers (39%) rather than the other categories of staff (11% or less) were mostly chosen to do so. For caregiver assessment, providers tended to choose social workers (50%), rather than nurses (39%) and physiotherapists/occupational therapists (33%). The same pattern prevailed for case management and counselling services.

Table 2 about here

Another way of interpreting the data is to begin with each profession and see what were the types of direct assistance its practitioners offer (see Table 2). Social workers usually provided counselling, case management, and caregiver assessment, and were sometimes chosen to lead support groups. Nurses were primarily involved in case management, caregiver assessment, centre-based caregiver training, and home-based caregiver training. Physiotherapists and occupational therapists offered caregiver assessment, centre-based caregiver training, and home-based caregiver training. As for the "others" category, they were engaged in counselling, case management, and spiritual care.

In addition to the services specified in the questionnaire, respondents were asked to indicate any other services they provided. These included public education talks and activities including road shows (n=4); loan of equipment (e.g. commodes, wheelchairs) (n=3); material

aid (e.g. milk formula, diapers, catheters, etc) (n=2); befriender service (n=1); family therapy (n=1); and a resource centre (n=1).

Service providers were asked about fee charging for the various services provided to caregivers. Less than half of the agencies (n=14) indicated "Yes", with some (n=8) adding qualifying statements that fees were charged for certain services (e.g. caregiver training or workshops) but not for others (e.g. support groups, counselling, and spiritual care). Other respondents (n=2) pointed out that their fees were subsidized or highly subsidized.

When asked whether there was an explicit agency policy to attend to both caregivers and care recipients, a majority (*n*=22) indicated "Yes." As to the number of caregivers served, the responses varied widely, between 30 to more than 3,500 (median=400). As for service expansion, eight respondents said their agencies had no plans to expand. Those who did plan expansions could be grouped into two categories: doing something new or doing "more of the same", such as more public education and outreach, counselling, support groups, caregiver training, information and referral. New services under consideration included grief counselling; self-help caregiver support groups; a social enterprise project to train caregivers; a drop-in centre for caregivers of older persons; and the establishment of a one-stop centre providing information and referral, caregiver training, and health/medical services.

The respondents were asked to identify the barriers that prevented caregivers from using the health and social services provided. Their responses could be organized broadly into three categories, pertaining to (i) caregivers, (ii) care recipients, and (iii) service providers. Most of the responses were associated with caregivers: they included time constraints, lack of awareness of services, transportation issues, costs of care, caregivers' responsibilities and attitudes, lack of alternate care, and distrust (see Table 3). A few respondents described barriers to seeking help posed by care recipients.

Table 3 about here

Challenges and Opportunities in Service Provision

This sub-section reports on various issues in providing caregiver support services, including the overlaps and gaps in services. The respondents were provided with a list of six issues and asked to indicate if they faced these challenges and to comment on these experiences. The majority cited funding (n=22), followed closely by programme attendance (n=21). Next on the list were staffing (n=21) and duplication or service gaps (n=20). The less problematic issues were knowledge/expertise (n=14) and identification of caregivers (n=13). In the following sections, these issues are described in more detail and the agencies' responses (where available) are presented.

Funding

A common theme in the responses was that non-profit service providers were required to raise funds, as the funding bodies usually do not provide full funding necessary for programmes, or provide funding for only a limited time, after which they would have to raise their own funds. Respondent 11 (a care coordinator) said that funding was not an issue as yet, since volunteers had been providing administrative support and volunteer nurses provided medical advice.

Programme Attendance

The obstacles to programme attendance were usually related to caregivers' attitudes or type of services provided. For example, Respondent 8 (a centre care manager) said parents of disabled children were more likely to participate than adult children of older persons;

Respondent 16 (a medical director) cited the lack of alternate arrangements for care recipients when their caregivers were attending programmes; Respondents 18 (a medical social worker) and 28 (a senior nurse) indicated poor attendance at psychoeducational meetings [designed to educate, support, and develop coping skills] or support group meetings.

Responses to this issue could be categorized thematically as tactical, programmatic, or service targeting. Tactical measures could be adopted to induce higher programme attendance. Respondent 1 (a medical social worker) observed that psychoeducation could be introduced as "part of compulsory attendance/service delivery". Modifications to the programmes could remove barriers to participation. Respondent 16 noted, "Caregivers are unable to attend, as patient becomes very sick or there is no one available to look after the patient when they go for training. We do training at patient's home, if needed." Respondent 24 (a care coordinator) said: "we provide elder-sitting." Respondent 28 suggested "telephone support in addition to the monthly meetings." Service targeting may involve changing the traditional service targets. Respondent 15 (an administrator) noted: "A lot of families are depending on full-time domestic helpers to take care of people with physical disabilities ... Many of these domestic helpers also have no emotional attachment with clients and are busy with various other domestic work."

Service Duplication and Service Gaps

A very small number of service providers (n=2) thought that service duplication was not necessarily a problem as it meant caregivers had access to more services and were able to benefit from services provided by other agencies. Most respondents identified gaps in services rather than duplication. These gaps included counselling for parents of children with autism, affordable respite care, and day care with extended operating hours.

Staffing

The respondents' comments on staffing issues usually referred to difficulties in the recruitment of various positions (e.g. nurses, homecare staff, social workers, and locally trained therapists); high staff turnover; work-load (particularly the need to juggle various programme responsibilities); and dependence on volunteers. Respondent 15 commented that, without reliable staff replacement, support groups had to be discontinued when experienced facilitators resigned.

Knowledge/Expertise

A few respondents (*n*=2) stated that they had competent and professional staff, and that consequently, knowledge/expertise was not an issue. Those who considered knowledge/expertise to be an issue (*n*=9), cited the following areas in need of improvement: care of persons with autism, caregiver issues, medical knowledge, and mental health awareness. Respondent 27 (a social work executive) commented that though lacking experience in leading support groups, his agency addressed this by asking for help from a counselling agency.

Identification of Caregivers

The issue on identification must be seen from the perspectives of both care recipients and caregivers. Respondent 10 (a senior social worker) said that some care recipients were unwilling to divulge information pertaining to their adult children because they did not want to impose on them. Most respondents described problems with adult children, in terms of responsibility and decision-making. Respondent 4 [a supervisor of medical social services] informed that "family members are divided as to who should be the caregiver" whereas respondent 5 (a medical director) commented that "caregiver and decision maker may not be

the same person"). The survey respondents indicated the importance of identifying a caregiver, mainly to ensure family responsibility and follow-up contact. Respondent 21 (a director of patient education) stated that the "hospital is firm in saying that there needs to be a caregiver." Caregivers must be identified if the agencies are to provide caregiver support. Respondent 30 (a medical social worker) stated that it is "essential to identify a caregiver so as to set goal for inpatient stay/rehabilitation and caregiver training before discharge." These agency responses should be placed in context; they were made by respondents in hospital and institutional care settings, most likely associated with the discharging of patients to their families and the community.

Advocacy for Family Caregivers

Lastly, respondents were asked what they wished to advocate for family caregivers. Their responses covered various caregiver needs. Most respondents emphasized financial support (n=11). They stressed assistance for caregivers who were low-income and often gave up their jobs to provide care when they could barely afford to do so. Several respondents (n=4) recommended financial assistance in the form of tax exemptions/rebates and caregiver allowances. Others (n=5) highlighted the need to encourage and support caregivers by ensuring recognition of their care work. The provision of affordable transport/escort services was also recommended to increase the usage of services (n=2).

There were some suggestions related specifically to respite care (*n*=7), that is, it should be accessible, available, and affordable. One comment related to care of those with dementia: dementia should be a national health priority and caregivers of persons with dementia should be allowed to use *Medisave* accounts (individual mandatory health savings accounts) to pay for medication and treatment (see Singapore's Ministry of Health website, www.moh.gov.sg/, for more information on health-care financing).

Discussion

The results of the survey show that most service providers offered counselling, case management, caregiver assessment, financial assistance, information, and caregiver training through various disciplines. A minority provided emergency care, short-stay respite care, daycare, and spiritual care. The list is quite similar to that reported in Feinberg *et al.* (2005), except for assistive technology/emergency response and home modifications, which were rarely provided. The study also reveals a specific concern with the needs of low-income and less educated caregivers, a group that is often overlooked when the research focus is on caregivers in general.

The discussion of the study findings is organized around three goals: reduction of barriers to caregiver support services; targeting hard-to-reach caregivers; and creating new areas of formal support.

Reduction of barriers to services

This study identifies several barriers to the usage of caregiver support services that are consistent with those mentioned in other caregiving studies. Research in the United States also shows that many caregivers do not use day care as respite because of inconvenient time scheduling or locations (Coleman, 2000). This study suggests several aspects of service delivery that have implications for service use, including availability, accessibility, and quality. A significant barrier is the availability of time, particularly for caregivers who are working full-time. Coleman (2000) noted that research has shown that caregivers are generally not receptive to services that place greater demands on their time, since they are already struggling with time management. Services for caregivers should be scheduled outside of normal working hours and during weekends.

Another barrier identified in the survey is that of transportation (see Table 3). Whittier et al. (2005) similarly found that a lack of available transportation was a barrier to accessing services, especially in suburban and rural areas. Where possible, service providers should offer transportation services and escort attendants, as needed, beyond the usual working hours to facilitate access by care recipients. As programme staff may be unwilling to work non-standard hours, financial compensation should be offered. For caregivers who lack alternate care, a "sitter" service would be helpful, either in the caregivers' homes (if, for example, care recipient is bed-ridden or homebound) or at the service venue. The quality of service itself has to be such that caregivers find it worthwhile to attend. In principle, providing home-based caregiver training "saves" travelling time, is more convenient for families whose care recipients are homebound, and facilitates personalized training. For service providers, however, it may be more costly to deploy staff to do home-based versus centre-based training. These costs have to be measured against the benefits of home-based initiatives, such as the prevention of institutionalization. Cost-benefit analysis is needed for such policy concerns.

Targeting hard-to-reach caregivers

Among caregivers, one group merits special attention—those who are illiterate, low-income, and poorly educated. They are often unaware of the services available to them. Physicians, particularly those in hospitals and clinics, who are likely to see caregivers, together with their care recipients, are a possible source of referrals. Fortinsky (2001, p. S35) observed that, for most caregivers of persons with dementia, "physicians are the first and only contact in the health care system" and, therefore, play a critical role in informing patients and caregivers of appropriate community-based services. Another source of referrals is social workers in family service agencies where caregivers sometimes apply for financial aid. As advised by Schofield (1998), for health professionals to expand beyond their usual role functions, organizational

and professional policies must endorse their role in "acknowledging, informing and supporting carers" (p. 230).

New areas of formal support

As this study and the current literature demonstrate, financial support for caregivers is critically important. Montgomery & Feinberg (2003) have highlighted the financial impact of caregiving as a greater issue for women since they are most likely to provide family care. They drew attention to the tax incentives available in some countries, which offer financial relief to family caregivers. They also compared how tax credits and tax deductions benefit low and high income families. They concluded that instead of tax relief, which does not benefit low income families as much, policy-makers should consider offering a care allowance to caregivers who give up their jobs because there is no one else to look after their care recipients. Australia offers benefits in the form of a carer allowance (non-means-tested) and carer payment (means-tested). In Germany, care recipients can choose whether to receive services provided by professionals or cash payments (less than the value of services), which can be used to pay informal caregivers, buy services in the market place, or buy goods unrelated to care (Montgomery & Feinberg, 2003; Wiener & Cuellar, 1999).

Policies should also recognize the financial needs of caregivers of those with dementias/Alzheimer's disease, and allow them to use Medisave accounts to pay for medication and treatment of their care recipients. Their inability to access their Medisave accounts may prompt some caregivers to admit their care recipients to hospitals to gain some respite for themselves and use Medisave to pay for the hospital costs (Ng, 2008).

Several respondents noted that their agencies were considering expansion and the establishment of new services. Still their primary concern was programme funding. Since fee payment from caregivers is not expected to be a major source of programme funding,

external funding (both public and private) should be made available to encourage service provision and the creation of new programmes that provide holistic services to caregivers and care recipients.

Limitations of the study

One limitation of this study is the under-representation of agencies serving persons with physical and mental disabilities, such as Down's syndrome, dyslexia, visual impairments and hearing impairments. The results of this study may not, therefore, be applicable to such services. Another limitation is a result of the use of a questionnaire, which tends to yield data lacking in depth. For example, most respondents referred to barriers to service usage in a general fashion. It would have been more useful to ascertain if barriers differ by types of services. More in-depth studies are required, particularly on the delivery of services that are client-centred. Yet another limitation is not being able to verify whether respondents are presenting their personal views or organizational views. Nonetheless, since both top management and programme staff were well represented, the study's findings encompassed both administration and implementation.

Concluding remarks

The resident population of Singapore aged 65 and older is projected to increase from 8.4% in 2005 to 18.7% in 2030 (Ministry of Community Development, Youth and Sports, 2006). As noted in several government reports (Ministry of Community Development and Sports, 1999; Ministry of Community Development, Youth and Sports, 2006, 2007), the family is expected to be the first line of support for older persons and persons with disabilities whereas the community provides a second line of support so as to prevent admission to institutional care. However, as many neo-liberal countries across the world, even in Asia, have realized, the

capacity of families to continue to provide care has been severely reduced by demographic trends, such as decreasing family size and increasing participation of women in the workforce (traditionally the major source of family caregiving) (Leow, 2001; Ng, 2007; Mason et al., 2006). The need to offer more caregiver support services has become pressing and will continue to increase. There is scope to expand support services for caregivers, particularly those who care for persons with disabilities: some service providers had given feedback that family caregivers of persons with disabilities tended to become overly dependent on professional aids in the care of their dependent family members (Ministry of Community Development, Youth and Sports, 2007). It is also time to develop an explicit plan to coordinate services among the various health and social service providers and to recognize the respective contributions of formal care providers and informal (family) caregivers. As this study has shown, service providers not only offer formal support but also act as strong advocates for family caregivers.

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Table 1. Types of Services Provided to Family Caregivers

Service Types	Specific Services	Number of	
		service	Percentage of
		providers	all providers
Information	Caregiving literature	22	69%
	Helpline	19	56%
Respite	Home support	19	56%
	Daycare service	11	32%
	Short-stay in institution	8	25%
	Emergency/overnight stay	3	10%
Supplementary	Financial assistance	24	73%
	Transportation	12	34%
	Meals delivery	5	16%
Direct assistance	Counseling	30	83%
	Case management	29	81%
	Caregiver assessment	25	69%
	Centre-based caregiver training	24	67%
	Support groups	17	47%
	Home-based caregiver training	16	44%
	Health & Welfare	12	33%
	Spiritual care	9	25%

Table 2. Services Provided by Professional Groups

	Social	Nurses	Physiotherapists/	Others (e.g. doctors,
	workers		Occupational	psychologists, pastoral
	Number	Number	therapists	care counselors,
	(%)	(%)		chaplain, teachers)
			Number (%)	Number (%)
Health & wellness	4 (11%)	6 (17%)	7 (19%)	2 (6%)
Spiritual care	6 (17%)	0 (0%)	0 (0%)	5 (14%)
Caregiver training (at home)	6 (17%)	13	9 (25%)	3 (8%)
		(36%)		
Caregiver training (centre-	11 (31%)	14	12 (33%)	2 (6%)
based)		(39%)		
Support groups	14 (39%)	4 (11%)	2 (6%)	0 (0%)
Caregiver assessment	18 (50%)	14	12 (33%)	3 (8%)
		(39%)		
Case management	23 (64%)	17	6 (17%)	7 (19%)
		(47%)		
Counseling	29 (81%)	11	5 (14%)	8 (22%)
		(31%)		

Table 3. Perceptions of Barriers to Service Usage

Categories	Themes	Examples of responses
Related to caregivers	Time (<i>n</i> =15)	RESPONDENT 1 (Medical Social
		Worker): Working full-time or part-time
		and cannot afford time to attend training;

		RESPONDENT 21 (: Lack time and are
		burdened by responsibilities.
	Costs of care	RESPONDENT 9 (Case Manager): Cannot
	(n=15)	afford nursing home care; RESPONDENT
		24: Financial concerns, unable to afford
		services.
	Lack of	RESPONDENT 4: Do not know where/how
	awareness of	to access such services; Respondent 10:
	services (<i>n</i> =14)	Some caregivers are illiterate, which
		hinders them in getting support.
	Caregivers'	RESPONDENT 4: Caregivers see formal
	responsibilities	training as time consuming, inconvenient,
	and attitudes	and not willing to pay for services.
	(n=7)	RESPONDENT 5: Conflicting roles in
		being parent to their own children and being
		a child to care recipient.
	Transportation	RESPONDENT 12 (Senior Care
	(n=4)	Coordinator): No doorstep transport service
		to day rehabilitation/care center.
	Lack of alternate	RESPONDENT 11 (Care Coordinator):
	care (<i>n</i> =4)	Several are keen but unable to attend due to
		lack of alternative caregiving arrangement.
Care recipients	Respect for care	RESPONDENT 11: Care recipients are
	recipients'	unwilling to be "baby sat" by someone
	preferences (n=3)	unfamiliar; RESPONDENT 21: Patients do

		not want caregivers to leave them alone
		because they are insecure.
Service providers	Means testing	RESPONDENT 24 (Care Coordinator):
	(n=4)	Unwilling to seek help, if subject to means
		testing.
	Lack of subsidies	RESPONDENT 25 (Medical Director,
	(n=3)	home care): No subsidies given for respite
		care.
	Agency /program	RESPONDENT 9 (Nursing home Care
	criteria (n=3)	Manager): Some caregivers cannot place
		care recipients in the nursing home as there
		is someone in the family who can take care
		of care recipient; hence, do not qualify for
		home admission.
	Mismatch	RESPONDENT 22 (Principal Medical
	between	Social Worker): Caregivers' training
	caregivers' work	program is conducted during office hours.
	hours and	
	agency's	
	operation hours	
	(n=1)	