Profiling The Dementia Family Carer In Singapore

Executive Summary

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The key findings of the study can be summarized herein:

1. The carer of a person with dementia (PWD) is typically a middle-aged daughter with at least 10 years of education and holding a full-time or part-time job. Many carers have to cope with other responsibilities and pursuits, and about 50% of the carers are assisted by domestic maids. The “successful” carer is likely one who can balance these multiple roles well. The competence, coping and welfare of domestic maids need to be considered given their intimate involvement in dementia care.

2. The level of carer burden is significant, with 27.2% of carers expressing feelings of burden more often than sometimes. It is hence important to screen for carer burden in any dementia service. The highest stress statements pertain to the need to multi-task, with carers having to juggle between caregiving and work as well as other family commitments. Carers have to cope with the guilt of not doing enough and the burden of feeling personally responsible for the Person With Dementia (PWD). Helping carers juggle multiple responsibilities and supporting them through feelings of not being up to the task and guilt is key.

3. Most carers express a strong desire to look after the PWD themselves at home. However they realize the difficulties involved and seek assistance. Possible ways to help carers include making it less costly to employ domestic maids (e.g. waive

levy), providing formal training and support in dementia care for domestic maids and giving an allowance to carers who wish to care for the PWD at home.

4. More outreach is needed for local dementia organizations while the media can help to increase awareness of the condition. Carers also expressed the desire for increased opportunities to speak to the attending doctor. There is a need to create more occasions for carers to interact and discuss with healthcare professionals about the care of the PWD. To this end, the provision of dementia counselling service for carers run by professionals may help.

5. About half of the carers in the study had never utilized dementia services because of time constraints and because some of them had to provide care full-time to the PWD. Respite and elder-sit services should be in place to free carers to attend training programmes and empower themselves with more knowledge, skills and support in their role. Many carers also felt that they could “obtain their own information” on dementia. This is an important group to target as they are likely committed and interested carers who may not realize the importance obtaining proper information and skills from dementia care professionals. Information obtained on their own should always be discussed with a professional to ensure correct interpretation and proper usage.

6. The commonest reasons cited for not using dementia services for the PWD (e.g. day care) pertain to the availability of a maid, failure to see the need for the service and refusal on the part of the PWD. Financial considerations, although not expressly stated, is likely to feature as well. Providing proactive education for

carers on the physical and psychological benefits of a structured day activity programme for PWD is a possible solution to this issue. Carers need to see day programmes as a viable form of treatment and not merely for respite. Other measures include making the day care more accessible by extending opening hours and improving transport coverage, making it more affordable with increased subsidies and improving the quality of the day programmes by going beyond generic programmes and adapting to the varied needs of different clients.

7. The expressed needs of the carers call for more formal training for carers in managing difficult behaviour in dementia as well as end of life care, more opportunities for carers to discuss issues about care of the PWD with doctors and other healthcare professionals, provision of better quality care and increasing the capacity of current dementia daycares, improving the competence of healthcare professionals in dementia care across all health sectors from acute hospitals to nursing homes and day cares, and providing better home care support for the PWD and the carer e.g. home medical care & nursing, elder-sit, end of life dementia care at home.