

Thirteenth Family Research Network (FRN) Forum: “Familial Caregivers and Their Impact on Resilience of Family Function”

27 April 2015

The thirteenth FRN forum considered the impact of informal caregivers in developing resilience in the family. The presentations at the forum focused on research that identified the challenges faced by familial caregivers of care recipients suffering from chronic illness and conditions. It was attended by 151 participants from the government, academia and the social service sector. The forum comprised four presentations followed by a discussion session moderated by Associate Professor Kalyani Mehta. In her opening remarks, Associate Professor Mehta referred to familial caregivers as the “forgotten army” and highlighted the need to provide them with support and make policies more accessible for them, especially as more Singaporeans are increasingly living longer lives which would lengthen the caregiving duration.

Presentation 1: “Families as Partners in Health Care Provision: The Case of Mental Health” by Dr Stella R. Quah (Adjunct Professor, Health Services and Systems Research, Duke-NUS Graduate Medical School)

Dr Quah shared the topline findings of a project on the interface between formal and informal care-giving and the role of familial caregivers in the context of schizophrenia (Quah, 2014). Her presentation covered a purposive sample of 47 family caregivers. In-depth interviews were conducted in addition to quantitative measurement of predictors, care burden, and contact between family caregiver and medical team.

De-institutionalisation trajectory

The typical care trajectory follows from “self-medication” to “family/informal care” and to formal medical care (either outpatient or inpatient). The de-institutionalisation of care is the inverse, i.e., moving patients back into family/informal care. The shifting of the burden of care from the medical team to the family caregiver firstly allows better management of limited healthcare resources. Secondly, returning the patient to his/her community/family may improve his/her health as patients tend to prefer family caregivers over high-tech and higher-trained paid/institutionalised care.

However, Dr Quah emphasised that a missing key element is the effective cooperation between the medical team and family caregiver. The design of medical services typically excludes family caregivers from the formal treatment process, notwithstanding the primary role of family caregivers in medical care in the home setting.

Possible barriers impeding effective partnership between family caregiver and medical team

There are two types of barriers that Dr Quah sought to test to see if they impeded effective collaboration between family caregiver and medical team. The first type is health services barriers, which comprise “norm of privacy”, “norm of autonomy”, and “norm of confidentiality”. All three health services barriers are actually the core of medical ethics and are meant to protect the patient and his/her rights.

The second would be assumed family barriers. These barriers consist of “assumed family disruptiveness” in which family caregivers are assumed to not contribute to the treatment process and are instead disruptive, wasting the medical practitioner’s precious time. Next is the “assumed family’s non-cooperation” whereby family caregivers are perceived to be uninterested in the patient’s treatment process. Last is the “expressed emotional hypothesis” that assumes that a patient’s relapse is caused by the family member/caregiver.

Health services barriers impeding effective partnership

Caring for the patient at home was found to significantly increase the family caregiver’s stress level. Additionally, the caregiver’s quality of life significantly decreases when they spend long hours (more than six hours a day) caring for the patient. More than half of family caregivers (52%) who were parents of the patient experienced high levels of stress compared to 25% of non-parent family caregivers.

Almost all family caregivers (94%) indicated that they needed information and guidance from the medical team to carry out their caregiving task well at home,. This indicated the family caregivers’ desire to contribute and be part of the medical team’s treatment process. Those who struggled to get in contact with the medical team tend to be the patient’s parent, aged over 53 years, have an unsatisfactory social network, and are likely to be unemployed as caregiving is a full-time occupation for them.

The expressed emotional hypothesis was not supported by the data because relapses were significantly associated with patient’s medication discontinuation in spite of the family’s best efforts to persuade the patient to take the medication as prescribed. Assumed family barriers were not existent as caregivers were found to desire contact with the medical team but encountered difficulty in getting it.

Multi-pronged approach to remove health services barriers

In cases where the illness, such as schizophrenia, renders the patient incapable of making rational decisions on his/her own care, the three medical ethics cannot be followed blindly and have to be reconsidered and the medical treatment process modified accordingly to include the family caregiver. Moreover, the medical team’s negative perception of the family caregivers has to be corrected. Finally, family caregivers and medical professionals could undergo systematic training to learn to work together to improve the patient’s well-being.

Presentation 2: “Families Living with Persons with Dementia” by Janhavi Vaingankar (Senior Manager, Research Division, Institute of Mental Health)

Ms Vaingankar presented global as well as local (Singapore) statistics on caregivers for persons with dementia. This presentation covered a study done on 63 informal caregivers of people with dementia using focus group discussions and semi-structured interviews.

Local statistics on dementia caregivers

Majority of the caregivers were women and 71% were aged about 50 years and over. There were about 74% of caregivers who had educational qualification lower than secondary level. Among the older care recipients, 65% had at least one symptom of behavioural or psychological symptom of dementia (BPSD). BPSD has been consistently linked with care burden or psychological impact on the caregiver. Moreover, 73% of persons with dementia required at

least some assistance with activities of daily living. About 20% of the caregivers reported receiving some help in caregiving from other family members or friends. Approximately 50% had paid help in care provision. Twenty per cent of dementia caregivers gave up or cut back on work. BPSD-related distress was found in 46% of caregivers and 11% were reported to have psychological morbidity, while 26% experienced burden of care. Care burden was found to be higher among caregivers who are married, caring for older adults who had high care needs, or whose care-recipients had at least one BPSD. Increased stress on caregivers also affected their care recipients' quality of life and often led to excessive service use, increasing healthcare and societal costs. It may also result in the institutionalisation of the care recipients.

Addressing caregivers' needs

In the era of de-institutionalisation, caregivers' needs have to be understood to support them in their provision of (long-term) caregiving at home. As there is a lack of understanding of caregivers' needs, the development of a measure of it can enable effective assessment of these needs and identify those with a higher magnitude of need. It can also facilitate resource allocation and inform policy and intervention.

Four distinct categories of caregiver needs

The first is the need for emotional and social support. It is important for others (family, friends, and community) to understand the situation (e.g., that the care recipient is indeed suffering from dementia) and support caregivers, such as through counselling and respite from emotional and physical strain (Vaingankar, 2013).

The second is the need for information such as guidance in recognising early signs of dementia, available treatments and services, and how to manage as the care recipient's dementia progresses. Information on administrative and legal requirements is also crucial as these matters can become overwhelming for the caregivers over and above their daily care responsibilities. There is also the need for information on managing behavioural issues and emergency situations for the caregivers.

The need for financial support includes assisting caregivers in balancing their employment and caregiving as well as engaging paid help.

The need for accessible and appropriate services and facilities forms the fourth category. Ms Vaingankar emphasised the importance of legal assistance for caregivers who may not know the requirements or the existence of certain legal requirements such as appointing a Lasting Power of Attorney.

Caregivers' Needs for Checklist for Dementia (CNCD)

The CNCD was developed and administered to 109 caregivers of older adults with dementia. As the sample group was small, the results could not be generalised. Unmet needs were found to be associated with lower education in the caregiver and BPSD-related distress. The results showed that the top three unmet needs were financial support, support from society and community, and affordable professional services. On the other hand, day-care centres' infrastructure was perceived to be adequate. Most of the respondents also felt that they had information on what to expect and on what to do as the care recipient's illness progresses, but the validity of this result is not known. Most also indicated that they did not have an issue with the availability of day-care centres.

There is a clear demand to address caregivers' needs. Information to identify the problem for making decisions and treatment are needed. It is also crucial for the family, society, employers, and healthcare providers to support caregivers. While the CNCD can serve as an easy-to-administer screening for identifying and assessing dementia caregivers' needs, studies involving larger samples are required for its further development and validation.

Presentation 3: “Family Caregivers of Older Singaporeans with Physical Disability: Impact of Caregiving and Role of Foreign Domestic Workers” by Dr Rahul Malhotra (Assistant Professor, Health Services & Systems Research Program, Duke-NUS Graduate Medical School Singapore)

Dr Malhotra's presentation utilised data from the Singapore Survey on Informal Caregiving (Chan, et al., 2012) to describe the socio-demographic characteristics of families of older Singaporeans with caregiving needs, and family support in eldercare received by primary informal caregivers and determining if support from foreign domestic workers moderates caregiving related outcomes. The sample group consisted of 1190 care recipient-caregiver dyads in which all care recipients have at least one limitation in activities of daily living (ADLs).

In testing the impact of informal caregiving by the presence of instrumental support from a foreign domestic worker, four primary stressors were identified to measure the care recipient's impairment — physical function, memory, behaviour and mood. Physical function is measured using the Older Americans Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire and a 24-item Revised Memory and Behaviour Problems Checklist (RMBPC) is used to measure the other three impairments. The Modified Caregiver Reaction Assessment was used to measure caregiving-related outcomes in four domains — disturbed schedule and poor health, lack of finances, lack of family support, and caregiver esteem.

Foreign domestic worker in informal caregiving

Dr Malhotra highlighted that the de-institutionalisation of care should not only be seen as from the formal hospital setting into the home setting but also into the community-based care setting. There is an increasing utilisation of community-based services but it is still inadequate though there have been positive moves in increasing both quantity and quality of these services. Nonetheless, most of the care is still carried out at home. Foreign domestic workers fall between the formal and informal sectors as they are not care professionals and, unlike informal caregivers, they are paid.

Women made up 69% of the surveyed care recipients. Over half (51%) of the care recipients had assistance from a foreign domestic worker. Mobility limitation was prevalent among the sampled care recipients. Most of the informal caregivers were aged 45 to 59 years (55%) and 60% were female. Among the caregivers, 60% were employed. Interestingly, 26% of sampled caregivers were never married. However, it is not known if they became caregivers because they were not married or that it is the other way round. Dr Malhotra pointed out that it is nevertheless a group worth looking into. Out of the caregivers who were children of the care recipients, 42% of daughters and 31% of sons who were never married would be without their own family caregivers in the future. Of the informal caregivers who received help from another person in assisting the care recipient in activities of daily living, 71% reported the person to be the foreign domestic worker.

Foreign domestic worker support beneficial to caregivers

It is found that the greater the impairment of the care recipient, the more detrimental it is for the caregiver. However, foreign domestic worker support is reported to be beneficial in various aspects of the caregiver's life, especially as the severity of the care recipient's impairment increases. Interestingly, foreign domestic worker support was found to be positive as family support. Although no data is collected on how long the foreign domestic worker has been with the caregiver, it is likely that she has either formed good relations or has been with the caregiver long enough to fill in the void of the possible lack of family support in caregiving the caregiver faces.

The number of foreign domestic workers in Singapore is likely to increase as caregiving demand rises. Compared to nursing homes, foreign domestic labour remains relatively affordable. Recent increase in concession for family with a person with disability indicated a positive direction by the government. However, Singapore is likely to encounter challenges in sourcing foreign domestic workers in the future as labour-supplying countries improve their economic conditions and impose stricter rules for improved work conditions in host countries, as well as issues concerning immigration and integration in the host country. Furthermore, there is concern about the impact of caregiving for the elderly, on the foreign domestic worker's mental and physical health. Dr Malhotra suggested including a self-rated health assessment during regular health checks and conducting a longitudinal study to monitor the health of foreign domestic worker.

Presentation 4: "Needs Assessment on Respite Care for Caregivers of Persons with Disabilities" by Dilys Tan (Manager, Disability, Service Planning & Development group, National Council of Social Service)

Ms Tan's presentation covered 925 caregivers of persons with disabilities, examining the caregivers' stress and focusing on the problem of limited respite care options in Singapore. Focus group discussions were conducted for 33 caregivers to design the questionnaire. Ms Tan pointed out that the study's use of a cross-sectional survey may lack contextual information on the respondents' cause of stress. The study is not representative as there was no national disability registry at the point of time it was carried out.

Child-centric view of respite care

Caregivers' understanding of respite care — defined as short-term care, usually in a nursing home or a hospice with the assistance of professional carers — was found to be low. Quality care for the child is a very important component in the respite care programme with child safety (72%) and trained personnel (59%) identified as the top and third most important factors, respectively. Most caregivers indicated day-care centres (86%) and residential homes (59%) as acceptable modes of respite care compared to in-home models, where a trained specialist comes over to the care recipient's home to take over caregiving (49%) or sending the care recipient to someone else's home (i.e., friends, relatives or neighbours) to be cared for (32%). This is consistent with caregivers' preference of trained or social workers (64%) over their friends and relatives (20%). Caregivers listed unplanned situations (e.g., feeling unwell, burnt-out or psychologically overwhelmed) as the times when they might most need respite care, indicating the view of respite care as a reactive measure rather than a preventive measure.

Factors for caregiver stress

Caregivers were reported to have poor mental health, and 65% indicated that caregiving duty is heavy and 63% felt burdened. It was found that the younger the care recipient, the higher the caregiver stress. This is likely due to challenges the caregiver faced in understanding and accepting the condition, especially when the child was newly diagnosed. Caregivers of care recipients with higher levels of disability also had high stress levels, likely because of more strenuous caregiving tasks. Moreover, a disability such as autism, which may include behavioural issues, causes more stress for the caregiver. Higher stress was reported for caregivers with lower income. Caregivers with higher education levels also had higher stress levels, possibly due to their higher expectations of their children or the compromises they have to make (e.g., at work) to provide caregiving. Additionally, presence of chronic illness is associated with higher levels of stress. Interestingly, caregivers with foreign domestic workers were found to have higher stress. It could be due to caregivers' expectation of well-trained help, and that it strains them to have to care for the care recipient while supervising the foreign domestic worker. Another explanation could be the caregiver's fear of the child's attachment to the foreign domestic worker, especially among younger parents.

Recommendations to relieve caregiver stress

Caregiver stress predicts the need for respite care. Caregiver-related factors such as chronic illness, higher education, and foreign domestic workers predicted the need for respite care more than care recipient-related factors.

Therefore, there is a need to prioritise caregivers' needs such as providing psychological health support programmes and provision of assistance for emergency situations. Information support for chronic illness for both the caregiver and care recipient could also be availed. Furthermore, training could be provided for foreign domestic workers in caregiving. Post-diagnostic support is also important to help caregivers to manage. Lastly, there is a need to promote awareness in caregivers to be pro-active in seeking help.

Discussion session (Question and Answer) moderated by Associate Professor Kalyani Mehta (Head, Gerontology Programme, School of Human Development and Social Services, SIM University)

Inclusive treatment process

Responding to the question on how social issues are identified, Dr Quah pointed out that the setup within medical treatment process for patients with mental illness (e.g., schizophrenia) is not supportive of including the caregiver, often due to the psychiatrist's limited time. However, there remains a need to allow the caregiver to seek advice, information, exchange views, and be involved in the treatment process. Even in instances where the caregiver is included, there is usually insufficient time for the caregiver to interact with the doctor. Dr Malhotra highlighted that there is also the concern with the quality of the consultation process. Dr Quah added that if the caregiver is included and is able to interact with the doctor, there is a need to ensure that the patient is not then being excluded.

Care provision continuation

A participant commented that more is required in terms of providing care for disabled persons who will never be independent, especially after their caregivers (e.g., parents) have passed on.

Impact on foreign domestic workers

The concern for the health of foreign domestic workers was raised as a participant shared about a transferred worker who was not properly fed in her previous employment. Foreign domestic labour agencies should also assess situations and stop supplying workers to families that have records of workers running away due to work stress. Continuous supply of workers to these families not only induces more stress for the families but also for the workers. Dr Malhotra emphasised the need for implementing health assessments for foreign domestic workers. Dr Mehta suggested the possibility of including assessment on their mental health, which could shed light on their stress levels as it may have impact on their care recipients.

Social impact of caregiving on family

Dr Quah shared that shifting of blame and disagreements in provision of care between family members (e.g., between spouses) can strain familial relationships and lead to break-ups. Additionally, a lack of support in sharing the burden of caregiving among family members can also strain relationships. There are also many never-married caregivers who take on the task of caregiving (of a sibling) after the parents pass away. On a positive note, when the parents who care for a child with schizophrenia passes away, the care recipient's siblings tend to gather to discuss the provision of caregiving. The task of caregiving usually passes on to the unmarried sibling. Dr Mehta pointed out that this is a case of a "caregiver by default". A participant added that if the caregiver is not married when taking on caregiving, he/she typically remains single after that. Other family members should be more involved in caregiving, but there is a tendency for the single sibling to assume 24/7 caregiving once the parents of a care recipient passes away.

Caregiving in other countries

Unlike other countries, Singapore has a high dependency on foreign domestic workers. Dr Mehta shared that, for example, there is a high level of civic consciousness in Japan where the neighbours and the community play a major role in helping out. Ms Vaingankar pointed out that primary care services and home nursing have also worked well in other countries. Dr Quah shared that European countries, US, and Canada have well-established formal care services but it is a fallacy to think that the patient does not require the family. Ms Tan highlighted that in the US, care recipients are encouraged to be more independent and community support is stronger. Dr Malhotra stressed the need to understand the funding mechanism of formal care services and the quality of these services have to be ensured. He highlighted that caregiving is context-specific and care provision models cannot be simply copied from other countries.

Going forward

Dr Mehta expressed the need to constantly check if care services are affordable and this includes respite care. There is also the need for proper organisation of information to allow caregivers to access it effectively.

Post-forum note: The Silver Caregivers Co-operative¹ has been set up to support and advocate for caregivers in Singapore.

1. See <http://www.silvercaregivers.org.sg/about-us.html>

References

- Chan, A., Ostbye, T., Malhotra, & Hu, A. J. (2012). Report of the survey on informal caregiving. Singapore: Ministry of Social and Family Development. Retrieved from <http://app.msf.gov.sg/Publications/The-Survey-on-Informal-Caregiving>
- Quah, S. R. (2014). Caring for persons with schizophrenia at home: Examining the link between family caregivers' role distress and quality of life. *Sociology of Health and Illness*, 36(4), 596–612.
- Vaingankar, J. A., Subramaniam, M., Picco, L., Eng, G. K., Shafie, S., Sambasivam R., . . . Chong, S. A. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. *International Psychogeriatrics*, 25(10), 1605–1619.