

UNIT NO. 6

CAREGIVER SUPPORT, TRAINING AND ENABLEMENT

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ABSTRACT

Caregiving burden is expected to increase as the number of people requiring daily assistance with their activities of daily living rises. Caregiver health has a direct impact on the ability to provide care as caregiver health has been shown to impact the level of care that caregivers offer. Hence, interventions that reduce this psychological distress and facilitate caregivers' quality of life are needed. While there are existing resources to support and enable caregiving, more may need to be developed in order to prepare for the future.

Keywords: Caregiving; Caregiver Support; Caregiver training; Enablement; Service coordination

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INTRODUCTION

It is estimated that there are approximately 210,800 caregivers in Singapore caring for seniors, children with special needs, the disabled, and the mentally and terminally ill (The Straits Times, 12 April 2004). This number is projected to increase as the numbers of people requiring daily assistance with activities of daily living will rise in the future, due to the ageing of the population, as well as the increase in physical and mental disabilities with rising life expectancy.

It is projected that by 2030, 20% of Singaporeans will be above the age of 65 (Ministry of Community Development, Youth and Sports, 2006). The increasing size of the elderly population relative to the younger cohorts will result in changes in the old-age dependency burden. The current ratio of seven adults aged 15-59 supporting one older person will shift to two adults supporting one older person in the year 2030. The disease profile in Singapore has also evolved, mirroring that of developed countries, which is shifting from communicable to lifestyle-related and chronic diseases associated with ageing, namely, cancer, heart disease, stroke and diabetes. Ongoing, rather than episodic management of these chronic diseases is essential to minimize the associated functional disabilities such as stroke from uncontrolled hypertension.

WHY IS CAREGIVING A CONCERN

Since the 1980s, various high level committees have been formed to address the challenges of an ageing population. In 2004, the Committee on Ageing Issues was set up to build on

the work done by previous committees. The Committee affirms support for older persons to age at home, in their own families and communities. The basic approach is that the family is considered the primary pillar of support, with community help as the next line (Mehta, 2007). As such, the Committee came up with a set of recommendations to support the family in their caring responsibilities. These included elder-friendly housing, a barrier-free and accessible environment for elders, improving the affordability of healthcare, and facilitating the elderly to be well-connected and active in society (Ministry of Community Development, Youth and Sports (MCYS), 2006).

Despite these measures, the strain on family caregivers is expected to rise. Family size is shrinking, dual-income families with traditional female caregivers in the workforce are rising and there is an increasing number of people who are unmarried (Mehta, 2007). These changes in social structure will lead to an increasing reliance on caregiving services.

The caregiver role is demanding, and for some whose disabilities are severe, it can be a lifelong responsibility. In a study of 61 family caregivers of homebound elders conducted by Mehta and Joshi (2001), three important findings emerged. First, there was an inverse relationship between the levels of stress of the carer and the physical dependency of the care recipient. Secondly, female caregivers were more likely to experience subjective burden and distress than their male counterparts. Thirdly, caregivers of patients suffering from Dementia, Hypertension and Parkinson's disease were relatively more stressed than other types of caregivers. Similarly, Pinquart and Sorensen's (2007) meta-analysis of 176 studies revealed that caregiver depressive symptomatology was the strongest predictor of physical health problems compared to other objective measures, such as number of chronic illnesses and socioeconomic status.

Research shows that poor caregiver health impacts on the caregivers' ability to provide care (De Frias et al., 2004; Hooker et al., 2002). Without adequate support and coping capabilities, caregivers are prone to exhaustion, emotional stress, financial and other care-related strains, resulting in caregiver burn-out and premature or unnecessary institutionalisation/hospitalisation of care recipients.

CAREGIVER EDUCATION, SUPPORT AND ENABLEMENT

Although caregiving can be stressful, its effects can be mitigated through caregiver education, support and enablement. A growing body of evidence indicates that caregiver education and support programs can delay nursing home placement and reduce the health care costs of care recipients (Cooke, McNally, Mulligan, Harrison & Newman, 2001; Mittelman, Ferris, Shulman, Steinberg & Levin, 1996).

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These reasons lead to the importance of interventions aimed at improving the situation for caregivers since preventing or minimizing caregiver burnout will help both caregivers and care recipients. These evidence-based treatments include a number of programs that seek to lessen caregiver burden and strain and to improve their psychological well-being—that is, reduce their levels of anxiety and depression. These programs differ and typically include a variety of educational and psychotherapeutic interventions, such as problem solving, coping-skills training, support groups, cognitive-behavioral therapy, and other types of individual and family counseling.

Brodaty, Green, and Koschera's (2003) meta-analysis of caregiver interventions found that those that targeted caregiver knowledge had the largest effect size. Caregiver knowledge is most beneficial, however, if the caregiver plays a more active role in knowledge acquisition (e.g., application of information through role-playing (Pinquart & Sorenson, 2006). Once the informational needs of the caregivers have been met, caregivers also benefit from training in general problem-solving skills, interventions that target managing the care recipient's behavior and the caregiver's own emotional response to caregiving.

Gallagher-Thompson and Coon's (2007) review of evidence-based psychological treatments identified three overarching categories: psychoeducational skill building, psychotherapy, and multicomponent interventions. Psychosocial intervention programs are designed to improve or increase the caregiver's skills in order to handle the caregiving situation, whereby providing relief to the caregiver and, at the same time, improving his or her caregiving capacity. The psychoeducational skill-building category focuses on educating caregivers about specific disorders (e.g., diabetes, stroke, Alzheimer's disease, etc.), as well as effective cognitive and behavioral problem-solving abilities specifically related to that disorder. The psychotherapy category involves forms of individual or group therapy or counseling. The final category—multicomponent—includes interventions that consist of two or more conceptually different approaches, such as participation in a support group, skill building, training, or respite care.

Pinquart and Sorenson's (2006) meta-analysis of more than 127 interventions found that multicomponent interventions were significant in delaying institutionalization as they are more intense and provide a broader array of services to caregivers. In another study of 199 caregivers of older adults with physical and/or cognitive problems, it was noted that caregiver depression decreased significantly after participating in a community-based caregiver support and training program that comprised skills training with a psychoeducational component designed to alleviate caregiver stress and burden (Huynh-Hohnbaum, Villa, Aranda and Lambdnos (2008).

In Singapore, hospitals and many other organisations, such as TOUCH Community Service and Tsao Foundation, now provide caregiver training, albeit in various forms. The Caregiver Training Grant from MCYS is now available to

caregivers. The Grant helps caregivers defray the cost of training and enable them to build their capabilities in caring for the physical and socio-emotional needs of their dependents. Regardless of income levels, families/caregivers can tap on an annual training grant of \$200 for every dependent under their care to attend approved training programmes. The Centre for Enabled Living (CEL), launched in 2009, is also working with Workforce Development Agency, Tsao Foundation, NTUC Eldercare and other training bodies to develop more structured training courses for both informal and formal caregivers.

When offering caregiver education programs, it is important to ensure that the program meets caregivers' needs, by considering the need for education on disease processes, coping skills, problem solving skills and support. It is important to decide whether the program should reach out to all caregivers or whether it should target particular subgroups of caregivers. Casting a broad net is appealing because it enables the organization to reach out to the largest possible group of caregivers. Programs that invite broad participation, however, have to keep education and training activities at a general level in order to be of interest to all participants. By targeting specific caregiver subgroups, it enables the trainer to impart specialized information and knowledge to caregivers of persons with particular health problems such as Alzheimer's disease. It also enables the trainer to engage caregivers who might otherwise not participate in a more general caregiver education and support program.

Program evaluation should be a routine part of any caregiver education and training program. At minimum, caregivers should be asked to evaluate the trainer, the usefulness of the program, what features were least and most helpful, and what uncovered issues should be included in future programs. More extensive evaluations can include assessments of the impact of a particular program on members' knowledge and skills, their ability to problem solve or to cope with pressing problems, or their well-being.

Over the last few years, there has been increasing support for family caregivers to empower and enable them to carry out their family caregiving role. New and expanded community-based services were established, run mainly by the volunteer organizations. These include programmes that provide home or community-based medical, nursing and rehabilitative care, palliative care, home help, day care, counselling and befriending. Some voluntary welfare organisations also provide counselling to family caregivers, while others run caregiver support groups.

KEY CHALLENGES AND IMPLICATIONS

Despite the availability of resources, it is recognised that there is still scope for more services to be provided in order for caregivers to be empowered as the first line of support for the elderly.

Service Coordination

The lack of core community-based services greatly impedes attempts to provide comprehensive care. In today's caregiving landscape, not many service providers are equipped to provide integrated home care services – comprising medical, nursing and social care. More can be done to ensure a more efficient delivery of person-centric care rather than service-centric care. For example, one still needs to tap on multiple service providers if the caregiver requires services such as home help and home therapy. One therefore needs to be very resourceful and creative in piecing together social services from the many community-based programs, which potentially can impede the ability to create a continuum of care. Adverse outcomes can ensue if services are poorly coordinated.

For this reason, the establishment of the Centre for Enabled Living (CEL) is a step in the right direction. CEL will enhance access to social care support services and schemes by acting as a convenient first-stop information agency. CEL would assess needs and list out the options available for the elderly and his/her caregivers to make an informed decision. CEL will also work closely with the Agency for Integrated Care to help persons who need care and their families navigate the continuum of medical-social services more efficiently.

Caregiver issues

Low-income families, facing multiple financial and social stress, are often unable to cope with caregiving burdens in the face of inadequate community-based support. This results in a poor quality of life for the older person and the family, and in some cases, premature placement in a nursing home, if and when such is available. Support of family members also cannot always be assumed. Some may not be in a position to help or family dynamics may be such that support is not feasible or acceptable. Caregivers with little family support may need more active outreach from professionals.

Bridging health and social care becomes even more critical and emphasis needs to be given to strengthening broad-based support for family caregivers through such interventions as training programmes, information services and mutual self-help networks. Opportunities should be provided for these

caregivers to talk through their concerns, fears and plans with a professional as they see fit, and at a time that is appropriate for them.

It is also necessary that national standards of training be developed and further research be conducted on care recipient outcomes and satisfaction, as well as assistive technologies to aid in caregiving. By designing programs that meet the needs of caregivers as they too age, we can begin to forestall and, perhaps, reverse the health and mental-health vulnerabilities associated with providing care over time.

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LEARNING POINTS

- **The number of caregivers is expected to rise in line with a growing elderly population and increasing physical and mental disabilities associated with rising life expectations.**
- **Caregivers are faced with multiple burdens, compounded by changes in social structure.**
- **Caregiver support, training and enablement programs are available to assist caregivers in their caregiving role, albeit more may need to be done in view of rising caregiver burdens.**