

## GUEST EDITORIAL

# Caring for caregivers after a stroke

Stroke usually occurs in the latter years of life, is sudden and all too often unexpected and unforgiving. When non-fatal, stroke, the second leading cause of disability after dementia, is nearly always disabling (World Health Organization (WHO), 2011). Due to common ensuing physical and cognitive impairments, many stroke survivors are unable to care for themselves in the following weeks, months, and possibly years (Lutz *et al.*, 2011). Thus, the caregiver role is instant and often long-term with no or very little time to adapt to the many, varied and immediate challenges.

As a disease of aging, the prevalence of stroke is expected to increase significantly as the world's population ages. And though in many developed countries the age-adjusted incidence of stroke is declining, the actual number of strokes is increasing due to the aging population (World Heart Federation (WHF), 2014). Currently, stroke accounts for almost 10% of all deaths worldwide and is the second leading cause of death for those aged 60 years and over (WHF, 2014). In 2005 an estimated 16 million people worldwide suffered a first-ever stroke, with an estimated prevalence of 62 million stroke survivors (Strong *et al.*, 2007); survivors who more often than not rely on informal family caregivers to support and care for them (Godwin *et al.*, 2013).

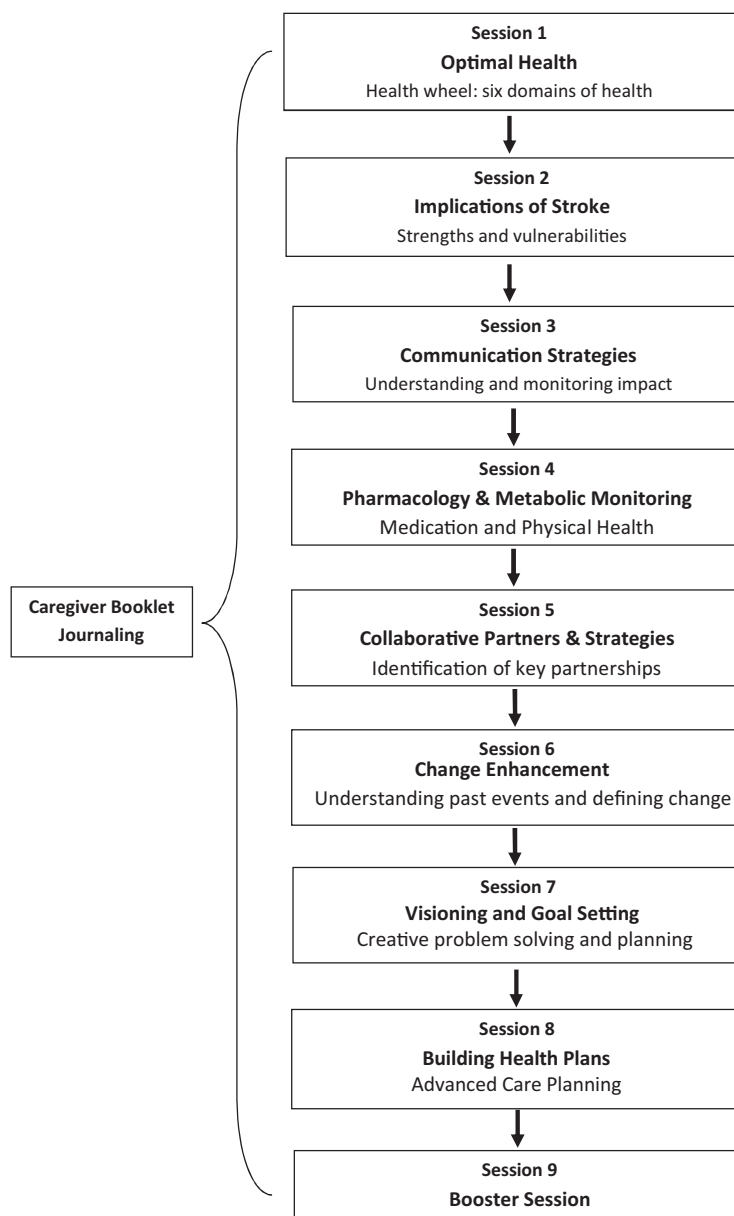
The needs of stroke caregivers are categorically different from those who care for relatives with progressive conditions such as dementia, because of the very nature of stroke – an abrupt, life-altering event. In addition, patients are facing shorter lengths of stay in hospital, which means a sudden shift from formal to informal care, placing further emphasis on the immediacy of the newly imposed caregiver role (Ski and O'Connell, 2007). Consequently, caregivers find themselves in a situation with no time to assist with functional limitations, arrange home modifications, adjust to the idea that recovery may not be complete, or deal with grief and loss that accompany stroke in a loved one (Lutz *et al.*, 2011).

In a meta-ethnographic review of qualitative studies, stroke caregivers were described as experiencing a “biographical disruption” to their lives, challenging and re-evaluating their own sense

of identity as a result of change and loss overlaid with uncertainty. There are often profound changes in roles, relationships and responsibilities, loss of autonomy, and disruption of “taken-for-granted” future goals and plans (Greenwood and Mackenzie, 2010). It is the diversity of challenges faced by those caring for a person affected by stroke that makes caregiver distress a complex and multilayered concept. Moreover, caregiving has been likened to chronic stress: indeed, Vitaliano *et al.* (2003) used the caregiving role as a model for analyzing the health effects of chronic stress.

The emotional, social, physical, and financial demands experienced when caring for an elderly individual with physical and cognitive limitations creates the perfect recipe for rapid mental health compromise. Not surprisingly, the onset of caregiver distress coincides with the initiation of the caregiving role; distress in caregivers has also been found to last over a year after the initial event and to be up to three times greater than that of the general population (Simon *et al.*, 2009; Green and King, 2010; National Institute of Mental Health, 2013). Further to this, caregiver distress has been identified as a leading cause of increased mortality for the caregiver and of the institutionalization of stroke survivors (Bakas, 2014). These findings highlight the importance of providing targeted mental health support for caregivers, which will improve the health and quality of life of the stroke patient.

The interdependence of stroke survivors and their caregivers is further highlighted in studies that have shown corresponding mental and physical health changes in the dyadic relationship. For example, caregiver depression exacerbates depression in the stroke survivor (Carnwath and Johnson, 1987), similar to the close association found over time between levels of stroke survivor stress and caregiver stress (Godwin *et al.*, 2013). Caregivers are a critical healthcare resource who save national healthcare systems vast sums each year (Arno *et al.*, 1999; Langa *et al.*, 2001). Given the direct impact of caregiver mental health on the level of care they are able to offer, pragmatic interventions specifically designed to support mental health of caregivers are warranted. In a review of the associated literature, Shultz



**Figure 1.** Stroke caregiver optimal health program.

and Sherwood (2008) expanded on this point by recommending that caregiver needs should be fully integrated into the planning and delivery of healthcare to older adults. However, this is yet to be achieved and the effectiveness of existing caregiver support programs remains to be established (Visser-Meily *et al.*, 2005; Smith *et al.*, 2008; Legg *et al.*, 2011).

Based on American Heart Association guidelines for classes and levels of evidence, a recent critical analysis by Bakas *et al.* (2014) of 17 caregiver and 15 caregiver/stroke survivor dyad intervention studies has produced evidence-based recommendations for the implementation and future design of stroke family caregiver and dyad interventions. In summary, interventions identified at the highest

level of evidence to enhance stroke family caregiver and dyads are those that:

1. combine skill-building (e.g. problem solving, stress management, goal setting) with psycho-educational strategies;
2. tailor interventions to the needs of stroke caregivers based on needs assessments along the continuum of care;
3. deliver the program face-to-face and/or by telephone; telephone interventions when in-person contact is not possible; and
4. offer the optimal number of sessions, which is between five and nine. Interventions spread across more sessions than this were identified as potentially impeding survivor and caregiver social functioning.

Bakas *et al.* (2014) advocate a focus on high quality studies drawing attention to intervention delivery; studies later in the stroke recovery process; and studies with longer-term follow-up, to establish the sustainability of the interventions. The evidence clearly points towards more rigorous design, multidisciplinary interventions, and sustainability of outcomes. In an effort to *close this treatment gap*, we have proposed a collaborative care program that adopts a person-centered approach to support the mental health of caregivers of stroke patients: the Stroke Caregiver Optimal Health Program (SCOHP: O'Brien *et al.*, 2014).

The integral feature of SCOHP is that it integrates caregiver support within health service care coordination. Enhancing self-efficacy is at the center of the program which, in turn, aims to improve caregiver self-management skills, optimization of mental health and the capacity to access key supports. By providing enablers for increased caregiver independence and empowerment, SCOHP works towards a shift in focus of the person's illness from being "dependent on" services to being "supported by" services. The emphasis is on collaboration between the facilitator and caregiver to achieve goals that stem from the caregiver's main concerns and needs. The facilitator encourages the caregiver to identify early warning signs of stress and illness and provides them with the skills to integrate healthy coping strategies to successfully manage stressful periods. SCOHP is structured in a way that encourages facilitators and caregivers to work together to develop viable health action plans and to discuss and arrange referrals in conjunction with the multidisciplinary team dependent on ongoing caregiver needs. Engaging with multiple clinicians can be daunting for informal caregivers; SCOHP facilitators assist in negotiating this complexity.

Based on a collaborative therapy framework (Castle *et al.*, 2006), the optimal health program was developed originally to support people with mental illness (Castle *et al.*, 2010; Gilbert *et al.*, 2012). Using the same framework and structure, SCOHP embraces a modular format tailored to various stages of the stroke illness trajectory, engaging consumers and clinicians from acute through to community care. To ensure sustainability and relevance, significant engagement with consumers was achieved when adapting the optimal health program to caregivers of stroke patients. The program is delivered in nine (8 + 1 booster session) sequential sessions based on a structured treatment manual (see Figure 1).

With an aging population worldwide, increased expectations and demands are being placed on family members to support those who have

experienced stroke. Described as the backbone of stroke healthcare services, caregivers play an indispensable role in patient care management and co-ordination. Unfortunately, the countless unpaid hours often come at the expense of caregivers' own health and well-being. In order for informal caregivers to adapt to and manage their new role effectively we propose SCOHP, which fosters caregiver empowerment via promotion of self-efficacy and integration with healthcare services. Furthermore, we recommend that these interventions be paired with continuous quality improvement via comprehensive short and long term, quantitative and qualitative process evaluations to ensure comprehensiveness of interventions and achieve sustainable outcomes.

### Conflict of interest

Nicola T. Lautenschlager is the current Editor-in-Chief of *International Psychogeriatrics*. Therefore, one of the deputy editors reviewed this editorial.

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