



Caregiver burden

Burden in caregivers of long-term stroke survivors: Prevalence and determinants at 6 months and 5 years after stroke



Krystyna Jaracz^{a,*}, Barbara Grabowska-Fudala^a, Krystyna Górna^a, Jan Jaracz^b, Jerzy Moczko^c, Wojciech Kozubski^d

^a Department of Neurological and Psychiatric Nursing, Poznan University of Medical Sciences, Poznan, Poland

^b Department of Adult Psychiatry, Poznan University of Medical Sciences, Poznan, Poland

^c Department of Computer Science and Statistics, Poznan University of Medical Sciences, Poznan, Poland

^d Department of Neurology, University of Medical Sciences, Poznan, Poland

ARTICLE INFO

Article history:

Received 3 December 2014

Received in revised form 30 March 2015

Accepted 12 April 2015

Keywords:

Stroke

Caregivers

Burden of illness

ABSTRACT

Objectives: To assess the prevalence of considerable burden among caregivers of stroke survivors at 6 months (Time 1) and 5 years after stroke (Time 2), to analyse changes in burden severity over time and to identify factors associated with the burden.

Methods: Eighty eight patient/caregiver pairs were assessed. Caregiver burden was measured with the Caregiver Burden Scale. Socio-demographic, stroke-related and psychological characteristics were analysed as potential determinants of the burden. Exact multiple logistic regression was used to identify the predictive factors.

Results: Considerable burden was reported by 44% of the caregivers at Time 1 and 30% at Time 2. The burden was independently associated with caregivers' sense of coherence and amount of time spent caregiving at Time 1, and with caregivers' anxiety at Time 2.

Conclusions: A significant proportion of the caregivers experienced considerable burden in the post-acute and chronic phases of stroke, although this proportion declined over time. Several characteristics were associated with the increased burden at different time points. All the independent predictors related to aspects of the carers.

Practice implications: Programmes including education about coping strategies and time management, as well as respite care provision, could be beneficial and might help to reduce the burden of caregiving.

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1. Introduction

The demographic ageing of societies and decreasing early stroke fatality rates have resulted in an approximately 84% increase in the absolute number of stroke survivors in the past few decades [1]. Nowadays, around 33 million stroke patients live worldwide and a sizable proportion of them suffer from moderate or severe disability [1]. According to recent studies, significant functional limitations are noted in 40–45% of the survivors in the first months after a stroke [2,3] and in around 30% after 5 years [4,5]. These patients need permanent or temporary care and

assistance with self-care and activities related to independent living in the home and community [6]. Because the majority of patients return to their own home after discharge from hospital, the help required is most often provided by family members.

Providing care may be highly demanding, due to the complex nature of stroke sequelae including physical, emotional, cognitive and behavioural changes, little preparation for caregiving tasks resulting from the suddenness of the illness, shortened length of hospitalisation and insufficient post-discharge support [7,8]. The caregivers may therefore experience adverse effects on their physical and emotional health, social activities, financial situation and spiritual functioning [9]. These consequences are termed “caregiver burden or strain” and are considered to be an important outcome of the caregiving process.

Many studies have shown that 25–46% of carers perceive a substantial burden during the first 6 months of caregiving [10–14] and that the average level of the burden is constant, or decreases

* Corresponding author at: Department of Neurological and Psychiatric Nursing, Poznan University of Medical Sciences, 11, Smoluchowski str., 60-179 Poznań, Poland. Tel.: +48 61 861 22 67; fax: +48 61 861 22 66.

E-mail address: jaracz@ump.edu.pl (K. Jaracz).

slightly over this period [11,14,15]. The first few months of caregiving have been recognised in the literature as “taking up the role” [16], a time when caregivers try to gain control of the situation and attempt to understand their new role, rearrange their everyday life, seek information and support, recognise the patient’s needs and learn the skills to meet them [17–19]. The severity of burden during this period is associated with both survivor and caregiver characteristics, among which greater post-stroke disability, disturbances of emotional health in both survivors and caregivers, as well as longer time spent in caring have been consistently found as determinants of the increased burden [20,21]. Our reports, and those of others, have additionally shown the importance of coping abilities for dealing with caregiving demands [22,23]. Qualitative studies have shown that a carer’s experience may change over time, along with skills development, the establishment of new routines, incorporating care responsibilities into daily life and developing coping strategies [19,24]. Therefore, one can posit that the burden may lessen with the passing of time. On the other hand, constant alertness, prolonged tiredness, a distorted social life and deprivation of personal needs may preserve, or even increase, the distress and burden [9,25,26].

So far, few studies have analysed changes in caregiver burden over time and, in the majority of them, the observation period did not exceed 12 months following the stroke or hospital discharge [20]. Only one study, that by Visser-Meily et al. [27], followed spouse caregivers for 3 years after stroke, examining their psychosocial functioning, including the burden. These authors found that the level of burden significantly declined over time. However, 43% of the caregivers still reported marked strain at the final examination.

Considering the fact that many stroke survivors require multi-year care, and that the adverse effects of caregiving may also be long-lasting, further prospective studies tracing the same patient/caregiver dyads seem to be important. Such studies would provide additional insight into the evolution of caregiving and would help to identify those individuals at risk of substantial burden.

The aims of the present study therefore were (1) to assess the prevalence of considerable burden among stroke survivors’ caregivers at 6 months and 5 years after stroke, (2) to analyse changes in burden severity over time, and (3) to identify factors associated with the burden at 6 months and 5 years following stroke, in order to know whether the burden and its determinants are similar or different at the post acute and chronic phases of stroke.

2. Methods

2.1. Participants

The study sample was recruited from caregivers of adult stroke patients consecutively admitted to a neurological department (which includes a stroke unit) between 2005 and 2008. The following inclusion criteria for the patients were used: a diagnosis of first-ever stroke, the presence of functional deficits according to the Barthel Index at discharge, absence of other disabling and/or psychiatric conditions, independence in activities of daily living (ADL) before stroke, and returning home after discharge. The exclusion criteria were: death during hospitalisation or after discharge, a final diagnosis other than stroke, transfer to institutional care, and refusal to participate. The inclusion criteria for caregivers were: to be the main person engaged in the care, not receiving payment for providing care, not providing long-term care for another person at the same time and agreement to participate.

2.2. Procedure

During the hospitalisation both the patients and their caregivers were informed about this study and the planned follow-up home visit for a face to face interview, at 6 months after discharge (Time 1, T1). One hundred and fifty patient/caregiver pairs entered the T1 assessment and the results have been published elsewhere [22]. Five years following discharge the study was repeated (Time 2, T2). The participants were contacted by telephone, by post, or personally, and invited to take part in the follow-up investigation. As a result, 118 patient/carer pairs were reached of whom 88 were seen for the T2 face to face investigation. Thirty pairs dropped-out because 25 patients had died, 2 patients had been transferred to a long-term care institution and 3 caregivers had stopped performing their role. Thirty two participants could not be located at all, despite several attempts. Consistent with the aims of the present work, only those who were assessed twice were eligible for the study. Therefore, the final sample consisted of 88 patient/caregiver pairs. The study was approved by the local bioethics committee.

2.3. Assessments

2.3.1. Carer measures

The Caregiver Burden Scale (CBS) [28], was used to assess the subjective burden. The CBS contains 22 items, scored from 1 to 4 (*not at all, seldom, sometimes, often*). These items are grouped into five subscales: general strain (8 items), isolation (3 items), disappointment (5 items), emotional involvement (3 items), and environment (3 items). The means of the five subscales, and of all 22 items, were calculated to obtain subscale scores and a total score ranging from 1 to 4, with higher scores indicating a more severe burden. According to the authors’ guidelines, a total score ≥ 2 designates a substantial burden [29].

The Hospital Anxiety and Depression Scale (HADS) [30] was applied for screening anxiety and depression. The HADS contains 7 items for the assessment of anxiety (HADS-A) and 7 for depression (HADS-D). The items are scored on a four point scale from 0 to 3, and possible total scores range from 0 to 21 for each subscale. Scoring 11 or more on both HADS-A and HADS-D indicates the probable presence of a mood disorder [31].

The Berlin Perceived Social Support Scale (PSS) [32], was used for measuring the available emotional and instrumental social support. The PSS consists of 8 items, scored on a four-point scale (*strongly disagree, somewhat disagree, somewhat agree, and strongly agree*). The total score is obtained by summing the item scores and ranges from 8 to 32. For the purpose of the present work, the PSS score was dichotomised into low and high, by taking the median as the point of division.

The Antonovsky’s Sense of Coherence Scale (SOC) [33], was chosen to assess the caregiver’s inner stress-coping resources defined, according to the SOC concept, as a personal disposition toward perceiving the world as comprehensive, manageable and meaningful that enhances the efficaciousness of strategies for coping with environmental stressors. The SOC consists of 13 items, rated on a seven-point Likert type scale, with a total maximum score of 91, with higher scores indicating a stronger sense of coherence. In accordance with previous research, values within the lowest quartile were considered as a weak SOC [34].

A single item of the WHOQoL-Bref [35] was used to measure the overall perception of health. This is a 1–5 point Likert scale, where 1 is very dissatisfied and 5 is very satisfied. For the purpose of this study the response range was dichotomised into two categories, namely unsatisfied (1–3 score) and satisfied (4–5 score). Additionally, a semi-structured questionnaire was used to document data on socio-demographic characteristics and time spent caring, which

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