

Outcome of Carer-Assisted Care for Stroke Survivors with Severe Disability: Preliminary Findings (Kesan Perawatan Dibantu Penjaga dalam Kalangan Penghidap Strok Kurang Upaya Teruk: Satu Kajian Awal)

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ABSTRACT

Involvement of informal carer in post-stroke care is important to prevent development of secondary complications particularly among stroke survivors with severe disability. However, to date, evidence on the benefit of stroke care training and involving carer to assist in the care for this group of stroke survivors is still limited. In this study, we evaluated the outcome of a carer-assisted care program for stroke survivors with severe disability who live at home. Sixteen stroke survivors with severe disability and 16 primary carers participated in this pre-test post-test intervention study. Carers were trained using a stroke care module which was developed by a group of multidisciplinary researchers from Universiti Kebangsaan Malaysia, prior to implementing the daily care for 8 weeks. Outcome of care on stroke survivors was assessed in term of change in disability level and quality of life using Modified Barthel Index (MBI) and EuroQol health-state measure (EQ-5D and EQ-VAS), respectively. While outcome of stroke care training on carer was determined using Modified Caregiver Strain Index (MCSI). Significant improvement is shown in the stroke survivors' EQ-VAS component of EuroQol health state measure (average increase by 12%, $t = 2.86$, $p = 0.01$) following the care. Although not statistically significant ($t = 0.97$; $p = 0.35$), the mean score of MCSI reduced by 14%. No significant change was found in the MBI of the stroke survivors at completion of the program. Carer-assisted care is useful in improving quality of life of stroke survivors and can potentially reduce stress level among carers. Larger study may assist in establishing these preliminary findings

Keywords: Stroke; carer-assisted care; disability; quality of life

ABSTRAK

Penglibatan penjaga tidak formal dalam perawatan pasca strok penting bagi mencegah komplikasi sekunder terutama dalam kalangan penghidap strok kurang upaya teruk. Namun hingga kini, faedah latihan perawatan strok dan melibatkan penjaga untuk membantu perawatan populasi penghidap strok ini masih terhad. Dalam kajian ini, kami menilai kesan program perawatan dibantu penjaga bagi penghidap strok kurang upaya teruk yang tinggal di rumah. Sejumlah 16 penghidap strok kurang upaya teruk dan 16 penjaga utama terlibat dalam kajian intervensi ini. Penjaga dilatih menggunakan modul perawatan strok yang dibentuk oleh penyelidik multidisiplin Universiti Kebangsaan Malaysia sebelum menjalankan perawatan harian selama 8 minggu. Kesan perawatan terhadap penghidap strok dinilai menerusi perubahan dalam tahap kurang upaya dan kualiti hidup menggunakan Indeks Barthel diubahsuai dan ukuran tahap kesihatan EuroQol (EQ-5D dan EQ-VAS). Manakala kesan latihan terhadap penjaga dinilai menggunakan Indeks Tekanan Penjaga Diubahsuai (MCSI). Perubahan positif yang signifikan ditemui bagi komponen EQ-VAS ukuran tahap kesihatan EuroQol (peningkatan sebanyak 12%, $t = 2.86$, $p = 0.01$) susulan perawatan. Skor min MCSI berkurang sebanyak 14%, namun tidak signifikan secara statistik ($t = 0.97$; $p = 0.35$). Tiada perubahan yang ketara didapati dalam skor MBI penghidap strok susulan intervensi. Kesimpulannya, perawatan dibantu penjaga bermanfaat dalam meningkatkan kualiti hidup dan berpotensi mengurangkan tekanan dalam kalangan penjaga. Kajian lanjutan dapat membantu menguatkan penemuan ini.

Kata kunci: Strok; perawatan dibantu penjaga; kurang upaya; kualiti hidup

INTRODUCTION

Stroke, an acute injury of the central nervous system caused by vascular lesion which leads to neurological deficit, is the most common cause of disability among older adults worldwide (Murray et al. 2012). According to the World Health Organisation (2015), stroke affected mostly the

population in low and middle-income countries, with men and women were equally affected. In Malaysia, stroke is one of the top five leading causes of death, and is among ten main reasons for admission into public hospitals (Loo & Gan 2012).

Stroke is also the main cause of severe long-term disability; ranked among the top 18 diseases contributing to

the loss of quality years lived (Benjamin et al. 2017). Severe disability refers to 'a state of inability to move without assistance,' is activity daily living (ADL)-dependent, and requires constant nursing care (Duncan & Pamela 1994). In many situations, the state of severe disability is worsened with the presence of secondary complications, such as falls, contracture, joints pain, depression and pressure sores which normally occur at 12 months or more post-stroke (Sackley et al. 2008). This imposes greater challenges to the stroke survivors as well as their carer whom in most situations, are the immediate family members.

Following a stroke, it is common for both the stroke survivors and the carers to experience challenging life changing episodes. Carer has to adapt to the transition of their role and responsibilities; with factors such as aging of carer, mental stress, and family support issues commonly interfering with the carer's coping ability (McCullagh et al. 2005; Jaracz et al. 2014; Loupis & Faux 2013; GBiri et al. 2015). Activities of stroke survivors which would require significant assistance and effort from the carer are numerous, which include feeding, dressing, transferring, bathing, skin care, getting medications and physical exercise (Hebel et al. 2014). In addition, carers play an important role in preserving stroke survivor's quality of life and ensuring rehabilitation gains in long term (Ganjiwale 2016). Improving knowledge among stroke survivors' carers will facilitate post-stroke recovery process; and among the most important educational needs are information about stroke complications, range of motion exercise, dietary intake and steps to modify health risk behaviour (Sowtali & Harith 2014). A local study reported that stroke carers' education needs were often unmet during the hospitalisation period of stroke patients due to multiple reasons (Nordin et al. 2014). Implementation of structured carer programs following acute stroke care period is required to address this unmet need.

A few studies have developed and tested stroke care modules or programmes to assist stroke survivors' carer in implementing their caregiving roles and responsibilities (Allen et al. 2002; Kalra et al. 2004; Shyu et al. 2010; Rodgers et al. 2014; Hebel et al. 2014). Contradictory results were reported, and due to the heterogeneity of the scope of these care modules, it is difficult to generalise the studies' findings to other stroke caregiver populations. Further studies are needed to establish the benefits of carer training program or care modules for carers. Therefore, the purpose of this study is to determine the outcome of a carer-assisted care program for stroke survivors with severe disabilities on the survivors' functional independence and quality of life and the carer's health state.

METHODOLOGY

STUDY DESIGN

This was a pre-test post-test experimental study to assess the outcome of a carer-assisted care for stroke survivors

with severe disability who live at home post-discharge from hospital. The study was approved by Universiti Kebangsaan Malaysia (UKM) Research and Ethics Committee, study code NN-2014-096.

PARTICIPANTS

Sixteen pairs of eligible participants consisting stroke patients and their primary carer were recruited. This sample size fulfilled the number of subjects required for a preliminary or a pilot study as documented in literature (Billingham et al. 2013). The inclusion criteria for stroke survivors were (1) aged 20 and above; (2) live at home and with the availability of carer; (3) confirmed diagnosis of stroke by medical officer, (4) in post-acute phase of stroke and (5) classified as having severe disability (score 4 and 5) based on the Modified Rankin Scale (Bonita & Beaglehole 1988). Stroke survivors who have (1) impaired physical function due to another conditions such as recent fracture, severe arthritis or other neurological disease; (2) medical illnesses in which movements are contra-indicated such as untreated deep vein thrombosis were excluded. The inclusion criteria for carers were (1) aged 18-70; (2) primary carer; (3) willing and able to provide care in home setting. Excluded carers were those with (1) known diagnosis of depression and (2) medical illness which limit ability to handle care-taking tasks such as severe backache, recent fracture and neurological conditions.

INTERVENTION

CARER-ASSISTED CARE MODULE

This study used a multidisciplinary carer-assisted care module which was developed by a group of UKM multidisciplinary health sciences researchers from physiotherapy, occupational therapy, speech sciences, nursing, health psychology and dietetic professions. The module consists of tasks to be carried out by carer in care-taking of the stroke survivors on a daily basis. Tasks and training delivery method were selected based on consensus of the researchers. Task descriptions and illustrations were provided in the care module to facilitate the carer in understanding each task before implementing them. In general, the care module consists of information on safety, care approaches for chest, skin, muscles and joints, and general hygiene, and techniques for communication, mobility and activity of daily living.

CARER TRAINING

Carer training was conducted twice by two physiotherapists and an occupational therapist who were trained to deliver training session based on the care module content. Each carer training session lasted for one and half hours, which consisted of explanation and demonstration and return-demonstration of tasks. During the training, carers had

opportunities to clarify any doubts and practise selective skills which were required in performing certain tasks. Carers were then asked to implement the structured care on a daily basis for eight weeks unsupervised. Carers were also asked to record each care session in a diary provided in the care module.

MONITORING

The therapists contacted each carer at week four to monitor compliance and review problems which might arise during the care implementation. Carers were also encouraged to contact the therapists during the 8-week care trial through phone for any related matters.

MEASUREMENT OF OUTCOME

Outcomes of the care intervention were measured at week nine by two independent assessors who were trained together for skills standardisation. Two sets of outcome were targeted; one for stroke survivors and another for carers. Outcome on stroke survivors were assessed in term of change in functional independence level and quality of life. While outcome on carers was determined in term of change in health state, which focused on stress level.

The patient's functional independence level was assessed using Modified Barthel Index (MBI). MBI consists of 10 domains of activities; bathing, dressing, grooming/personal hygiene, feeding, toileting, bowel/bladder control, stair climbing, transfer to bed/chair, toilet transfer and walking. Patients were observed while doing the activities except for toileting, bowel/bladder control and toilet transfer domains, which were via self-report by carers. Scoring of each domain was based on a given scoring system, following which scores for each domain were summed up to produce a total score. The total score was used to interpret stroke survivors' dependency level; total dependency (0-24), severely dependent (25-49), moderately dependent (50-74), mild dependency (75-90) and minimal dependency (91-99). MBI is a sensitive tool and possesses high inter-rater reliability. It shows valuable changes over time and demonstrates precise scoring of ADL tasks (Fricke & Unsworth 1996).

EuroQol health state measure was used to measure the quality of life of the stroke survivors. The questionnaire has two components; EQ-5D-3L, which is a five-dimension health questionnaire on mobility, self-care, usual activities, pain/discomfort and anxiety/depression and EQ-VAS which assess general health state. EQ-5D-3L provides three response options for each question namely 1 = no problem, 2 = some/moderate problem and 3 = major/severe problem, while for EQ-VAS, respondents were asked to nominate health state score which range from 0 = 'worst imaginable health state' to 100 = 'best imaginable health state.' EuroQol health state measure has higher validity and

responsiveness for chronic condition compared to Short Form-6 dimensions (SF-6D) questionnaire (Obradovic & Liedgens 2013).

Carers' stress level was assessed by using Modified Caregiver Strain Index (MCSI), a 13-question tool used to measure caregiver's stress related to care provision. It consists of several domains, which are financial, physical, psychological, social and personal. Three options of response are available for each item in each domain, namely 'yes', 'sometimes' and 'no', which carries a score of 2 points, 1 point and 0, respectively. Seven or more positive responses on the index indicate high level of strain of the carer. MCSI shows high internal and test-retest reliability coefficient (Onega 2013).

DATA ANALYSIS

Data was analysed using the Statistical Package for Social Sciences (SPSS) version 23. Demography of participants were analysed descriptively and reported in term of the mean and standard deviation (SD) or frequency and percentage (%) where relevant. Changes in all outcomes were analysed by comparing the mean (SD) values of pre and post intervention using paired t-test or Wilcoxon signed ranked test. Level of significance was set at $p < 0.05$.

RESULTS

CHARACTERISTICS OF THE PARTICIPANTS

All 16 stroke survivors with severe disability (mean age \pm standard deviation (SD) = 77.0 \pm 11.3 years) and 16 primary carers (mean age \pm SD = 50.0 \pm 7.1 years) completed the care trial. Table 1 and 2 show the characteristics of the stroke survivors and the carers, respective.

TABLE 1. Characteristics of stroke survivors (n = 16)

Characteristic	Categories	Mean (SD) or n(%)
Age, years	-	Mean (SD) = 76.88 (11.33)
Gender	Female	12 (75)
	Male	4 (15)
Ethnicity	Malay	9 (56.25)
	Chinese	5 (31.25)
	Indian	1 (6.25)
	Others	1 (6.25)
Type of stroke	Ischemic	5 (31.25)
	Hemorrhagic	4 (15.00)
	Unclassified	7(43.75)
Modified Rankin Scale (MRS) score	4	4 (15)
	5	12 (75)

TABLE 2. Sociodemography of the carers (n = 16)

Characteristic	Categories	Mean (SD) or n(%)
Age , years		50.31 (7.12)
Gender	Female	15 (93.75)
	Male	1 (6.25)
Ethnicity	Malay	9 (56.25)
	Chinese	3 (18.75)
	Others	4 (25%)
Employment	Employed	4 (25.00)
	Unemployed	10 (62.5)
	Pensioner	2 (12.5)

Changes in MBI, EuroQol and MCSI through the intervention are shown in table 3. No significant changes were found for MI and EQ5D-3L scores following the care implementation. However, there is an improvement in the stroke survivors' EQ-VAS score by 12% ($t = 2.86$; $p = 0.01$). The mean score \pm SD of MCSI among carers reduced from 8.69 ± 6.31 to 7.44 ± 6.15 , which is a reduction of 14%. However, the change was not statistically significant ($t = 0.97$; $p = 0.35$).

TABLE 3. Comparison of the scores of MBI, EQ5D, EQ-VAS and MCSI at pre and post intervention

	Pre	Post	Difference	Effect size	p
Patients' outcome measures					
MBI [median(range)]	5.50(0-37)	4.0(0-43)	0 [(-6)-12]	$r = 0.62$	0.08**
EQ5D Mobility [median(range)]	3.00(2-3)	3.00(2-3)	0.00 [(-1)-0]	$r = 1.00$	0.83**
EQ5D Self-care [median(range)]	2.00(2-3)	3.00(2-3)	0.00 [(-1)-0]	$r = 1.00$	0.46**
EQ5D Usual Activity [median(range)]	3.00(2-3)	2.00(2-3)	0.00 [(-1)-0]	$r = 1.00$	0.16**
EQ5D Pain [median(range)]	2.00(1-3)	2.00(1-3)	0.00 [(-1)-1]	$r = 0.00$	1.00**
EQ5D Anxiety [median(range)]	2.00(1-3)	2.00(1-3)	0.00 [(-1)-1]	$r = 0.33$	0.56**
EQ VAS [mean(SD)]	51.75 (12.15)	58.00 (10.33)	6.25 (8.73)	$d = 0.56$	0.01*
Carers' outcome measure	8.69 (6.31)	7.44 (6.15)	-1.25 (5.13)	$d = 0.20$	0.35*
MCSI [mean(SD)]					

DISCUSSIONS

Our study intended to assess the outcome of a carer-assisted care program for stroke survivors with severe disabilities on the survivors' functional independence level and quality of life and carer's stress level. We found that carer training and care module implementation improved the stroke survivors' general health status by 12% after 8 weeks, although no significant change in the stroke survivor's disability level was obtained. This finding is consistent with results from a study by Allen and colleagues (2002) in which stroke patients who completed a structured care program shown better health profile at 3 months post discharge. In general, a patient's health status is influenced by various functional domains which include physical function such as ability to perform activity of daily living, emotional and social functioning. Providing adequate caregiving training assists carers to be more capable in fulfilling the multiple needs of stroke survivors.

Other than better quality of care provided by carers following training, knowledge on how to communicate effectively with stroke survivors which gained through the training facilitated better interactions between stroke survivors and the carers, thus improving the survivors' emotional status. On a contrary, a study by Rodgers and co-researchers in 2014 found that group education program to caregivers of stroke survivors yielded no significant benefit in improving perceived health status of stroke survivors. In the study, some carers perceived group education sessions

as unable to cater for the stroke survivor's specific practical and emotional needs. The negative results in their study could be due to the content of the education program, in which issues related to carers' psychological needs were not addressed. Practical sessions on specific care-taking tasks are also important education component to carers and stroke survivors which were lacking in their program.

Caregiving for stroke survivors with severe disability may cause burden to caregivers in various aspects. Results of our study show that, although not statistically significant, carers' stress level reduced by 14% after 8 weeks of participation in the care program. Our findings support the results of a large study by Kalra and co-researchers (2004) in which reduction of emotional burden and improvement of quality of life among carers following a carer training program were reported. In the study, 300 pairs of stroke patients and primary carers underwent training of basic nursing and personal care techniques for 30 to 45 minutes in three to five sessions depending on their need, following which their competencies were assessed. Hafsteinsdóttir and colleagues (2011) highlighted that following stroke, carers to stroke survivors concerned more on the correct way to perform basic handling which include transferring, lifting, bathing and performing exercises, and ways to handle emotional changes and dietary needs. These concerns were addressed in the care module used in our study, which may have produced positive result on the carers. In our study, reduction of MCSI score failed to achieve a statistically significance level. This could be due

to a marked increase in the stress level among four new carers who may still be in the phase of adapting with the changes in life. Jaracz and co-authors (2014) stressed that the first few weeks of caregiving are the most challenging phase for carers due to low coping ability and high anxiety level. In our study, two carers also reported increased stress due to financial issue, which is beyond the scope of the care module. Caregiver's age also influenced caregiver satisfaction with their life and affect their stress level. A study by Anderson and colleagues (2013) reported that young family caregiver with age lower than 65 years old, perceived lower life satisfaction compared to caregiver between age 18 to 64 years old. As mean caregiver's age in this study is 50 years old, they are considered young caregiver and more prone to report higher stress level caused by multifactorial issues despite better condition of their physical health.

Recovery following stroke is influenced by various factors and stroke survivors with severe disability normally experience slower improvement (Bonita & Beaglehole 1988). Our care program could not significantly improve stroke survivors' level of functional independence as measured using MBI. The significant state of disability among the stroke survivors in our study which more than 75% of the survivors are severely disabled and only 25% are moderately disabled based on MRS could be the main reason for this unfavourable result. This indicates the need for a longer duration of care to obtain change in functions. Our finding is consistent with findings of larger studies by Shyu et al. (2010) and Hebel et al. (2014). The researchers reported that a care givers intervention program and a 2-hour hospital-based group education program did not significantly enhance patients' self-care and functional ability, and suggested more intensive sessions are required.

Our study is not without limitations. The main limitation is, been a preliminary study, the findings are subjected to external validity issue. Nonetheless, our study is among a few studies which involved the implementation of a multidisciplinary care module on stroke survivors with severe disability. Most past studies recruited stroke survivors who were 'more abled' as such, the extent and burden of caretaking on carers' health state could not be fully evaluated. Our study adds knowledge to the existing stroke literature in this topic. This program could be improved by adding psychological component for carer and adding practical sessions on dietetic component in the program.

CONCLUSION

In conclusion, the implementation of carer-assisted care is beneficial to assist stroke survivors with severe disability and their carers in obtaining better health status. Carer-assisted care should be implemented in a larger study to establish these findings.

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