

The moderating role of caregiver preparedness on the relationship between depression and stroke-specific quality of life in stroke dyads: a longitudinal study

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Aims

To examine the moderating role of caregiver preparedness on the association between stroke survivors' depression and stroke-specific quality of life dimensions.

Methods and results

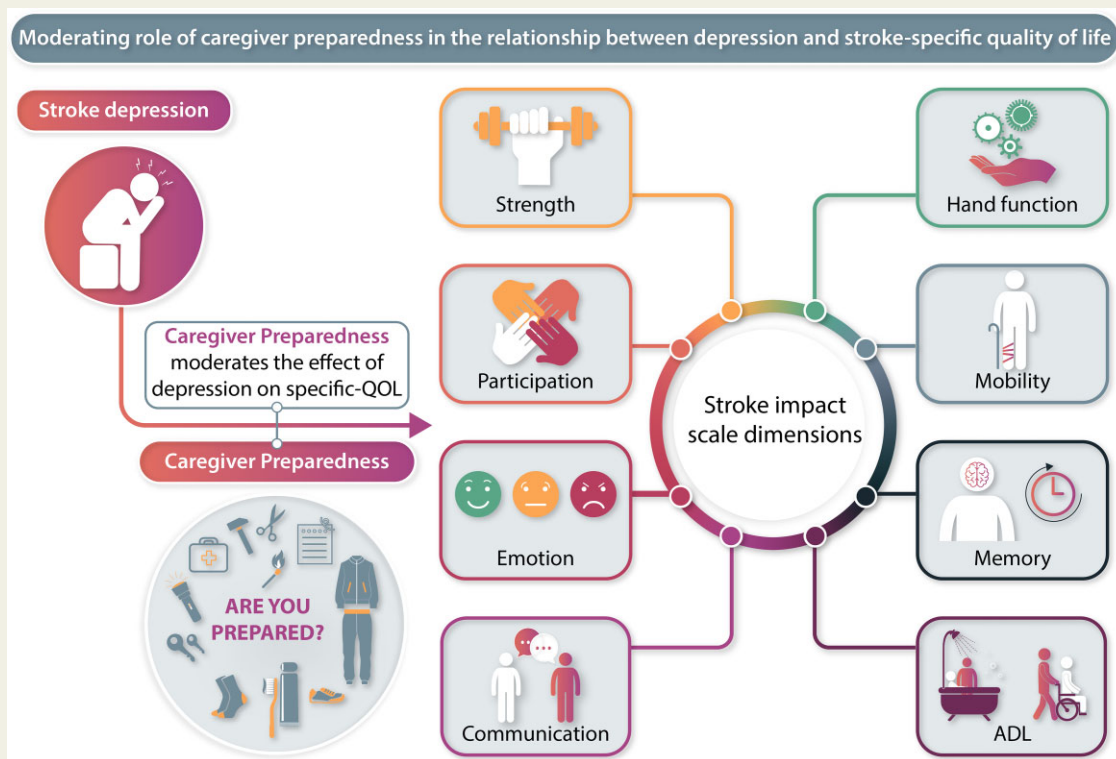
We used a multilevel modelling approach to analyse trajectories of change in the eight Stroke Impact Scale 3.0 subscales [i.e. strength, communication, mobility, activities of daily living (ADL)/instrumental activities of daily living (IADL), memory, emotion, hand function, participation] using Hierarchical Linear Modeling. Caregiver preparedness significantly moderated the association between survivor depressive symptoms and survivor communication ($B = -0.95$, $P < 0.01$), mobility ($B = -0.60$, $P < 0.05$), and ADL/IADL ($B = -0.73$, $P < 0.01$) at baseline; linear change for strength ($B = 0.83$, $P < 0.05$) and communication ($B = 0.66$, $P < 0.05$); and quadratic change for strength ($B = -0.19$, $P < 0.01$). Although caregiver preparedness did not significantly moderate the association between survivor depressive symptoms and strength at baseline, there was a significant moderating effect for change over time. Higher levels of caregiver preparedness were significantly associated with higher survivor scores of emotion, hand function, and participation at baseline.

Conclusions

Including immediate caregivers in the care process, through a psycho-educational training, would mean having better-prepared caregivers and consequently more-healthy stroke survivors. Given that preparedness includes coping with stress, responding and managing emergencies, assessing help and information may require tailored interventions aimed at improving the caregivers' skills and knowledge about stroke survivors' management.

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Graphical Abstract



Keywords

Survivors • Caregiver • Preparedness • Depression • SIS

Novelty

- This study provides knowledge about the moderation effect of caregiver preparedness between depression and QOL in stroke survivors.
- Knowledge about the interdependence between caregivers and stroke survivors are provided.

Introduction

Stroke represents the first cause of disabilities and one of the first cause of mortality worldwide.¹ In the USA, more than 795 000 people have a stroke every year,² while in Europe it affects about 1.1 million inhabitants.³ Stroke is also responsible for about 140 000 deaths in the US and 400 000 in Europe every year.³ As populations continue to grow and live to an older age, stroke events and their long-term sequelae, and the corresponding costs, are expected to increase dramatically.⁴ In 2017, the cost associated with stroke was estimated at €45 billion (Wilkins E, 2017), including direct and indirect costs of care provision and productivity loss.⁵

After stroke, stroke survivors usually experience stroke-related problems, such as mood disorders, aphasia, dysphagia, hemiplegia,⁶ and poor social interaction,⁷ which could have a significant impact on stroke survivors' psychological health. Hackett and Pickles⁸ have demonstrated that depression is common in 33% of stroke survivors, which affects functional outcomes, recovery and leads to higher mortality. In addition, studies^{9,10} have observed that depressive symptoms in stroke survivors

lead to lower stroke physical⁹ [i.e. strength, hand function, mobility, memory, activities of daily living (ADL), communications, and emotion] and emotional quality of life (QOL) dimensions.¹⁰

However, authors supposed that there could be moderator variables that could moderate the effect of a variable (i.e. depression) on an outcome (i.e. QOL). In their conceptual framework, which focused on QOL in stroke survivor–caregiver dyads, they identified the caregiver preparedness as a possible moderator variable, which could play an important role on this association. Past studies have analysed the role of the caregiver preparedness in the stroke population. For example, authors observed that caregiver preparedness was usually associated with a reduction of caregiver burden,^{11,12} of anxiety¹³ and improved outcomes of depression¹⁴ in stroke survivors, while a lack of preparedness was associated with higher caregivers' depressive symptoms, poor physical health, higher strain.¹⁵

Although several authors^{9,10} have analysed the role of caregiver preparedness in the stroke population, to our knowledge, only one study¹⁶ has previously described the moderator role of caregiver preparedness on the association between depression and QOL in

stroke survivor–caregiver dyads, evaluated with a generic instrument. This represents a gap in the literature, because the generic QOL could capture aspects of recovery related to daily living while the disease-specific QOL could be more sensitive to identify changes related to stroke condition, for example the hand function and strength due to hemiplegia, mobility, communication ability (i.e. after aphasia), social participation, etc. Knowing the moderation role of the caregiver preparedness on the association between depression in stroke survivor–caregiver dyads and QOL could be important because it would be possible, through this knowledge, to develop tailor interventions that could improve caregiver preparedness and consequently moderate the effect of depression on their QOL.

For these reasons, the aim of this study was to examine the moderating role of caregiver preparedness on the association between stroke survivors' depression and stroke-specific QOL dimensions [Stroke Impact Scale (SIS)].

Methods

Design

For this study, a longitudinal design was chosen through which dyads of stroke survivors and their caregivers were enrolled from the time of discharge from the rehabilitation hospital for 1 year, with data collection at baseline (T0) and at 3 (T1), 6 (T2), 9 (T3), and 12 months (T4). Protocol and data are part of a larger study published previously where it is possible to know the details.¹⁷ Specifically, this study was a cohort study aimed to analyse the stroke survivors' and caregivers' QOL during the first 12 months after stroke survivors' discharge.

Participants and setting

A sample of 243 stroke survivor–caregiver dyads was enrolled for the study. Participants of this study were enrolled at survivor discharge from 10 rehabilitation hospitals in several cities across Italy: Viterbo, Tivoli, Rome, Grottaferrata, Potenza, Guidonia, Cosenza, Ragusa, Naples, and Taranto. Inclusion and exclusion criteria were defined for both, if a member of the dyad did not meet the inclusion criteria, the dyad was excluded. The inclusion criteria that concerned the stroke survivor were: a diagnosis of stroke found via computed tomography or magnetic resonance imaging, and a discharge from a rehabilitation hospital, while they were excluded if: had a previous stroke, a reduced level of consciousness or aphasia, a severe condition that could be associated with poor quality of life, severe pre-existing deficits secondary to other clinical conditions such as multiple sclerosis or dementia. With regard to the caregivers of stroke survivors, inclusion criteria were considered: to be identified as the main informal caregiver without being paid, and gave their consent to participate in the study. Once the dyad was identified and the study authorization was received, follow-up meetings were planned, and by appointment, the researchers were able to collect the data necessary for the study at the home of stroke survivors.

Instruments

For measuring depression in stroke survivors, we used the Hospital Depression Scale (HDS) which is one of the two scale of the Hospital Anxiety and Depression Scale (HADS). The HDS is composed of seven items with a score range between 0 and 21. A score higher than eight indicates depression¹⁸ and higher scores indicate greater depression. Several studies have tested the validity and reliability of the HADS in different patient and caregiver populations¹⁹ including the Italian population²⁰ showing

good validity and reliability. In the present study, the HDS showed good reliability in both stroke survivors ($\alpha = 0.80$) and caregivers ($\alpha = 0.79$).

To evaluate the survivors' stroke-specific QOL, we used the SIS 3.0.²¹ The SIS 3.0 is a 59-item instrument, including eight subscales: strength, hand function, mobility, memory, ADL, communications, emotion, and participation. Each SIS 3.0 item uses a five-point Likert-type scale for responses. Summative scores are computed per each subscale (range 0–100), with higher scores indicating better QOL in that specific domain. Stroke Impact Scale 3.0 was previously tested also in Italian population, which showed good reliability and validity.²²

To evaluate caregiver preparedness, we used the Caregiver Preparedness Scale (CPS), an eight-item instrument measuring caregivers' preparation to care for a patient's physical and emotional needs, including setting up services, coping with caregiving stress, making caregiving activities pleasant for him/herself and the patient, responding to and managing emergencies, getting help and information from the health care system, and overall preparation. The score of the CPS ranges between 0 (unprepared) and 4 (very well prepared). This instrument has been tested in stroke caregivers, showing good validity and reliability, with a Cronbach's alpha higher than 0.90.²³

We also collected sociodemographic data on the survivors and caregivers, including age, gender, educational status, employment status, and stroke–caregiver relationship (e.g. spousal relationship), and clinical data on the survivors, such as comorbidities and site and type of stroke.

Data analysis

We used descriptive statistics, including means, standard deviations (SDs), frequencies, and percentages to describe survivor and caregiver sociodemographic characteristics. We used a multilevel modelling approach to analyse trajectories of change in the eight SIS 3.0 subscales [i.e. strength, communication, mobility, ADL/instrumental activities of daily living (IADL), memory, emotion, hand function, participation] using Hierarchical Linear Modeling v7 (Skokie, IL, USA). Stroke Impact Scale trajectories were analysed by assessing each dimension during five time-points (baseline, 3, 6, 9, and 12 months post-discharge). To determine the moderating role of caregiver preparedness on the association between survivor depressive symptoms and each SIS domain, interaction terms were created by first centring each variable (i.e. caregiver preparedness and survivor depressive symptoms) and then multiplying the centred variables together. A significant interaction effect was deemed evidence of moderation. Figures depict high (1 SD above the mean) and low (1 SD below the mean) levels of each variable. When non-significant interaction effects were found, we reported simpler models including only the main effects of caregiver preparedness and depressive symptoms. Each model controlled for baseline covariates [i.e. survivor age, gender, employment status, educational status, stroke site and stroke type, survivor physical function, and caregiver type (spouse vs. non-spouse)].

Ethical consideration

The Institutional Review Boards of each rehabilitation hospital in which participants were enrolled approved the study. We fully informed the stroke survivors and the caregivers about the study protocol, and we obtained a signed consent form from each survivor and caregiver enrolled in the study before data collection.

Results

Description of the sample

The 243 stroke survivors included in the current study were, on average, 70.84 (SD = 11.8) years of age. Half the sample was women

Table 1 Stroke survivor characteristics (N = 243)

Characteristic	M (\pm) or n (%)
Age (years), mean (\pm SD)	70.84 (\pm 11.8)
Female	121 (50)
Employed	40 (17)
More than middle school education	75 (31)
Stroke type (% ischaemic)	189 (78)
Stroke site (% right hemisphere)	118 (49)
Spouse caregiver	87 (36)
Patient physical function (0–100)	57.02 (\pm 29.03)
Depressive symptoms (0–21)	9.58 (\pm 4.33)
Caregiver preparedness (0–4)	1.94 (\pm 0.86)
Strength (SIS) (0–100)	40.84 (\pm 25.47)
Communication (SIS) (0–100)	77.34 (\pm 22.14)
Mobility (SIS) (0–100)	46.72 (\pm 29.03)
ADL/IADL (SIS) (0–100)	45.62 (\pm 28.55)
Memory (SIS) (0–100)	70.31 (\pm 24.54)
Emotion (SIS) (0–100)	57.18 (\pm 17.21)
Hand function (SIS) (0–100)	36.33 (\pm 30.97)
Participation (SIS) (0–100)	43.55 (\pm 29.03)

Note. SIS, Stroke Impact Scale; ADL, activities of daily living; IADL, instrumental activities of daily living.

(50%) and half the sample was men. Survivors were predominantly not working (83%), had ischaemic strokes (78%), and were cared for by a non-spouse (64%) (see [Table 1](#)).

Caregivers were 52 (SD = 13.9) years of age. The majority of them was female (66%), retired (52%), living with stroke survivors (63%). Just over a third of survivors and caregivers were married to each other, with half of the survivors cared for by an adult child. At baseline, the stroke caregiver had an average. Mean caregiver preparedness at baseline was 1.6 (SD = 0.9).

Patterns of change in stroke impact

Multilevel modelling results for survivor stroke-specific QOL demonstrated quadratic (non-linear) patterns of change for all eight subscales (see [Figure 1](#)). Although patterns varied across the eight domains, there was a general improvement over time, particularly for the five domains that had the lowest scores at baseline (i.e. hand function, strength, participation, ADL/IADL, and mobility).

Relationship between depression and stroke impact scale dimensions

Relationship between stroke survivors' depression and SIS dimensions is described in [Tables 2 and 3](#). At baseline, stroke survivors' depression was negatively associated with all SIS dimensions. Indeed, stroke survivors with higher depressive symptoms had lower strength ($B = -0.99$, $P < 0.01$), communication ($B = -1.22$, $P < 0.001$), mobility ($B = -0.81$, $P < 0.01$), ADL/IADL abilities ($B =$

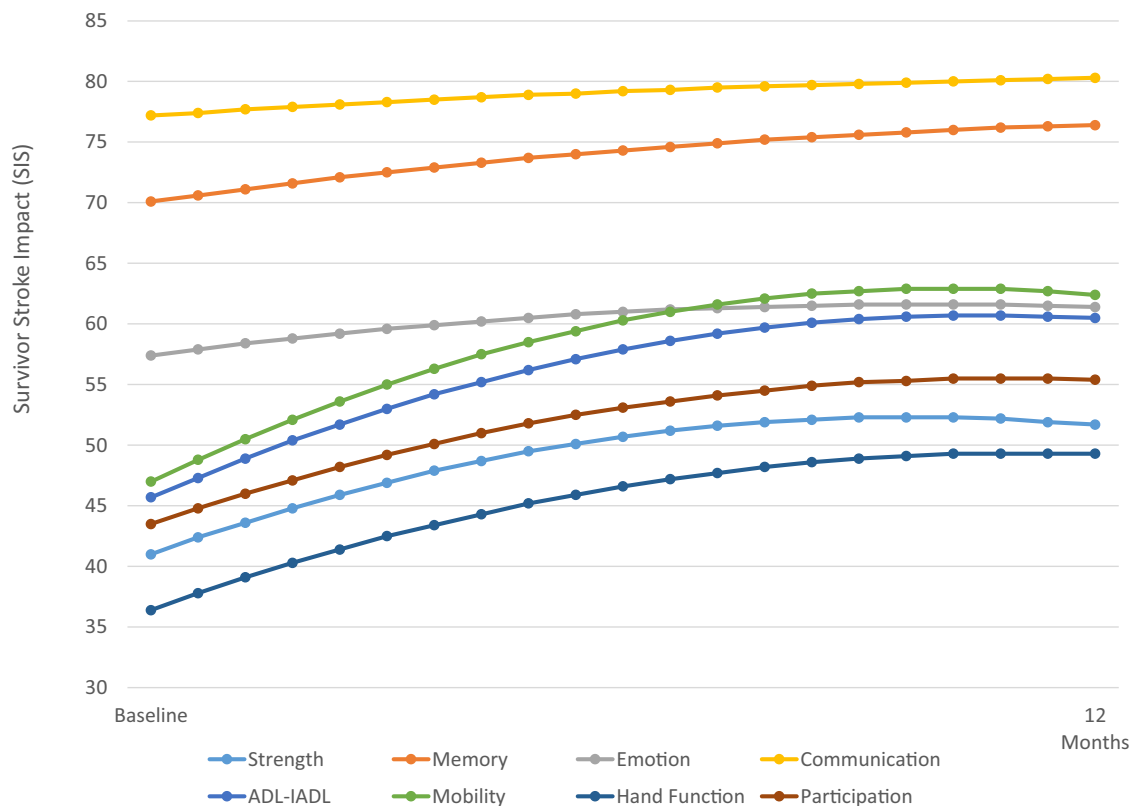
**Figure 1.** Trajectories of stroke survivors' SIS dimensions.

Table 2 The moderating role of caregiver preparedness in the association between survivor depressive symptoms and survivor stroke-specific quality of life over time (N = 243)

Variables	Strength B (SE)	Communication B (SE)	Mobility B (SE)	ADL/IADL B (SE)
Intercept ^a	38.47 (3.10)***	76.79 (2.89)***	46.71 (2.49)***	47.91 (2.23)***
Survivor age	0.22 (0.13)	-0.20 (0.12)	0.02 (0.11)	-0.10 (0.09)
Survivor gender	0.15 (2.83)	1.28 (2.64)	-2.87 (2.28)	-4.67 (2.03)*
Survivor employment	-2.20 (3.97)	-1.48 (3.70)	-3.58 (3.20)	-0.56 (2.84)
Survivor education	3.62 (2.99)	0.15 (2.79)	0.35 (2.41)	3.74 (2.14)
Stroke type	-1.11 (3.32)	-4.93 (3.09)	-1.07 (2.68)	-2.30 (2.37)
Stroke site	0.66 (2.69)	-2.44 (2.51)	1.30 (2.17)	-1.38 (1.93)
Survivor physical function	0.39 (0.05)***	0.21 (0.04)***	0.69 (0.04)***	0.72 (0.04)***
Survivor depressive symptoms	-0.99 (0.36)**	-1.22 (0.34)***	-0.81 (0.29)**	-0.56 (0.26)*
Caregiver type	3.95 (3.08)	3.68 (2.88)	3.32 (2.49)	-0.09 (2.21)
Caregiver preparedness	1.63 (1.60)	-1.26 (1.49)	2.59 (1.29)*	3.38 (1.14)**
Survivor depressive symptoms * caregiver preparedness	-0.64 (0.38)	-0.95 (0.35)**	-0.60 (0.30)*	-0.73 (0.27)**
Linear slope ^b	2.30 (2.83)	-4.74 (2.52)	2.48 (2.70)	2.48 (2.59)
Survivor age	-0.30 (0.12)**	-0.01 (0.10)	-0.29 (0.11)**	-0.22 (0.11)*
Survivor gender	4.86 (2.56)	3.49 (2.28)	6.36 (2.44)**	5.11 (2.37)*
Survivor employment	4.85 (3.49)	-0.42 (3.10)	4.85 (3.32)	3.66 (3.18)
Survivor education	-0.65 (2.66)	0.37 (2.36)	-0.85 (2.53)	-2.31 (2.42)
Stroke type	3.68 (3.19)	0.58 (2.82)	1.97 (3.04)	1.92 (2.90)
Stroke site	1.69 (2.39)	3.60 (2.13)	4.36 (2.28)	3.26 (2.18)
Survivor physical function	-0.09 (0.05)	0.02 (0.04)	-0.22 (0.05)***	-0.23 (0.04)***
Survivor depressive symptoms	0.21 (0.33)	0.56 (0.29)	0.02 (0.31)	-0.05 (0.30)
Caregiver type	-0.17 (2.71)	5.95 (2.42)*	2.59 (2.58)	4.25 (2.47)
Caregiver preparedness	2.08 (1.43)	1.99 (1.27)	-0.23 (1.36)	-1.11 (1.30)
Survivor depressive symptoms * caregiver preparedness	0.83 (0.33)*	0.66 (0.30)*	0.51 (0.31)	0.45 (0.30)
Quadratic slope ^c	0.16 (0.61)	0.95 (0.50)	-0.02 (0.59)	-0.10 (0.55)
Survivor age	0.06 (0.03)*	-0.01 (0.02)	0.06 (0.02)*	0.04 (0.02)
Survivor gender	-1.30 (0.55)*	-0.55 (0.46)	-1.44 (0.54)**	-1.02 (0.50)*
Survivor employment	-0.91 (0.75)	0.01 (0.62)	-0.86 (0.73)	-0.68 (0.68)
Survivor education	-0.19 (0.57)	-0.16 (0.47)	0.03 (0.55)	0.27 (0.51)
Stroke type	-0.90 (0.70)	-0.07 (0.57)	-0.41 (0.68)	-0.22 (0.63)
Stroke site	-0.35 (0.51)	-0.42 (0.42)	-0.84 (0.49)	-0.54 (0.46)
Survivor physical function	0.01 (0.01)	-0.01 (0.01)	0.03 (0.01)**	0.03 (0.01)***
Survivor depressive symptoms	-0.06 (0.07)	-0.09 (0.06)	0.02 (0.07)	0.03 (0.05)
Caregiver type	-0.01 (0.58)	-1.33 (0.48)**	-0.13 (0.56)	-0.59 (0.52)
Caregiver preparedness	-0.38 (0.31)	-0.19 (0.25)	0.09 (0.30)	0.31 (0.28)
Survivor depressive symptoms * caregiver preparedness	-0.19 (0.07)**	-0.10 (0.06)	-0.11 (0.07)	-0.09 (0.06)

B represents an unstandardized coefficient generated in HLM.

^aThe intercept has been coded to represent baseline scores on subscales of the Stroke Impact Scale (SIS).

^bThe linear slope represents instantaneous change at baseline.

^cThe quadratic slope represents the acceleration or curvature in rate of change per 3 months in each SIS subscale over the 12-month period. Depressive symptoms and preparedness were centred around their mean.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

-0.56, $P < 0.05$), memory ($B = -1.35$, $P < 0.001$), emotion ($B = -2.45$, $P < 0.001$), hand function ($B = -1.41$, $P < 0.001$), and participation ($B = -1.54$, $P < 0.001$). Differently, analysing the association

between stroke survivors' depressive symptom and SIS dimensions over time, we observed a negative association only on memory and emotion.

Table 3 The role of caregiver preparedness in survivor stroke-specific quality of life over time (N = 243)

Variables	Memory B (SE)	Emotion B (SE)	Hand function B (SE)	Participation B (SE)
Intercept ^a	71.12 (3.23)***	56.21 (1.77)***	42.45 (3.14)***	42.83 (2.49)***
Survivor age	-0.19 (0.14)	0.08 (0.08)	0.04 (0.13)	0.02 (0.11)
Survivor gender	0.02 (2.97)	0.22 (1.63)	-10.24 (2.87)***	-2.57 (2.29)
Survivor employment	0.28 (4.14)	-1.48 (2.27)	-0.65 (3.99)	0.99 (3.19)
Survivor education	1.73 (3.12)	-0.20 (1.71)	0.37 (3.02)	0.76 (2.40)
Stroke type	-6.14 (3.47)	0.61 (1.90)	1.13 (3.36)	-1.93 (2.68)
Stroke site	-1.02 (2.81)	0.35 (1.54)	-0.21 (2.72)	-0.35 (2.17)
Survivor physical function	0.22 (0.05)***	0.09 (0.03)**	0.59 (0.05)***	0.38 (0.04)***
Survivor depressive symptoms	-1.35 (0.38)***	-2.45 (0.21)***	-1.41 (0.37)***	-1.54 (0.29)***
Caregiver type	0.23 (3.24)	2.01 (1.77)	-2.12 (3.13)	6.02 (2.49)*
Caregiver preparedness	1.66 (1.68)	2.22 (0.92)*	5.20 (1.62)**	4.21 (1.29)***
Linear slope ^b	-7.41 (2.83)**	1.41 (1.86)	1.09 (2.94)	2.77 (2.41)
Survivor age	0.02 (0.12)	-0.17 (0.08)*	-0.39 (0.12)***	-0.30 (0.10)**
Survivor gender	5.51 (2.57)*	0.83 (1.69)	4.86 (2.65)	3.89 (2.19)
Survivor employment	-2.07 (3.51)	-2.32 (2.28)	3.60 (3.59)	0.17 (2.97)
Survivor education	0.58 (2.67)	-0.13 (1.74)	-0.66 (2.74)	2.15 (2.26)
Stroke type	5.48 (3.17)	1.29 (2.11)	-0.41 (3.30)	-0.97 (2.74)
Stroke site	4.07 (2.40)	1.03 (1.57)	3.11 (2.47)	1.59 (2.03)
Survivor physical function	0.07 (0.05)	-0.02 (0.03)	-0.15 (0.05)**	-0.06 (0.04)
Survivor depressive symptoms	0.87 (0.32)**	0.63 (0.21)**	0.46 (0.33)	0.06 (0.27)
Caregiver type	10.27 (2.74)***	0.12 (1.78)	3.22 (2.81)	0.56 (2.31)
Caregiver preparedness	0.71 (1.43)	0.12 (0.93)	5.20 (1.62)**	-0.30 (1.21)
Quadratic slope ^c	1.66 (0.54)**	-0.34 (0.42)	-0.10 (0.59)	-0.16 (0.52)
Survivor age	-0.01 (0.02)	0.04 (0.02)*	0.08 (0.02)***	0.06 (0.02)**
Survivor gender	-0.97 (0.49)	-0.11 (0.38)	-0.68 (0.53)	-0.83 (0.48)
Survivor employment	0.38 (0.67)	0.58 (0.51)	-0.66 (0.72)	-0.16 (0.65)
Survivor education	-0.15 (0.51)	0.23 (0.39)	0.10 (0.55)	-0.39 (0.49)
Stroke type	-1.28 (0.62)*	-0.55 (0.48)	0.19 (0.67)	0.12 (0.61)
Stroke site	-0.64 (0.46)	-0.10 (0.35)	-0.52 (0.49)	-0.22 (0.44)
Survivor physical function	-0.02 (0.01)*	-0.01 (0.01)	0.02 (0.01)*	0.01 (0.01)
Survivor depressive symptoms	-0.15 (0.06)*	-0.09 (0.05)	-0.05 (0.07)	0.02 (0.06)
Caregiver type	2.14 (0.52)***	0.16 (0.39)	-0.34 (0.56)	-0.01 (0.50)
Caregiver preparedness	-0.02 (0.27)	-0.02 (0.21)	0.08 (0.29)	0.18 (0.26)

B represents an unstandardized coefficient generated in HLM.

^aThe intercept has been coded to represent baseline scores on subscales of the Stroke Impact Scale (SIS).

^bThe linear slope represents instantaneous change at baseline.

^cThe quadratic slope represents the acceleration or curvature in rate of change per 3 months in each SIS subscale over the 12-month period. Depressive symptoms and preparedness were centred around their mean.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

The moderating role of caregiver preparedness on stroke impact

Table 2 shows the significant moderating role of caregiver preparedness on the association between survivor depressive symptoms and four SIS domains (i.e. strength, communication, mobility, and ADL/IADL). Caregiver preparedness significantly moderated the association between survivor depressive symptoms and survivor

communication ($B = -0.95$, $P < 0.01$), mobility ($B = -0.60$, $P < 0.05$), and ADL/IADL ($B = -0.73$, $P < 0.01$) at baseline; linear change for strength ($B = 0.83$, $P < 0.05$), and communication ($B = 0.66$, $P < 0.05$); and quadratic change for strength ($B = -0.19$, $P < 0.01$).

Although caregiver preparedness did not significantly moderate the association between survivor depressive symptoms and strength at baseline, there was a significant moderating effect for change over

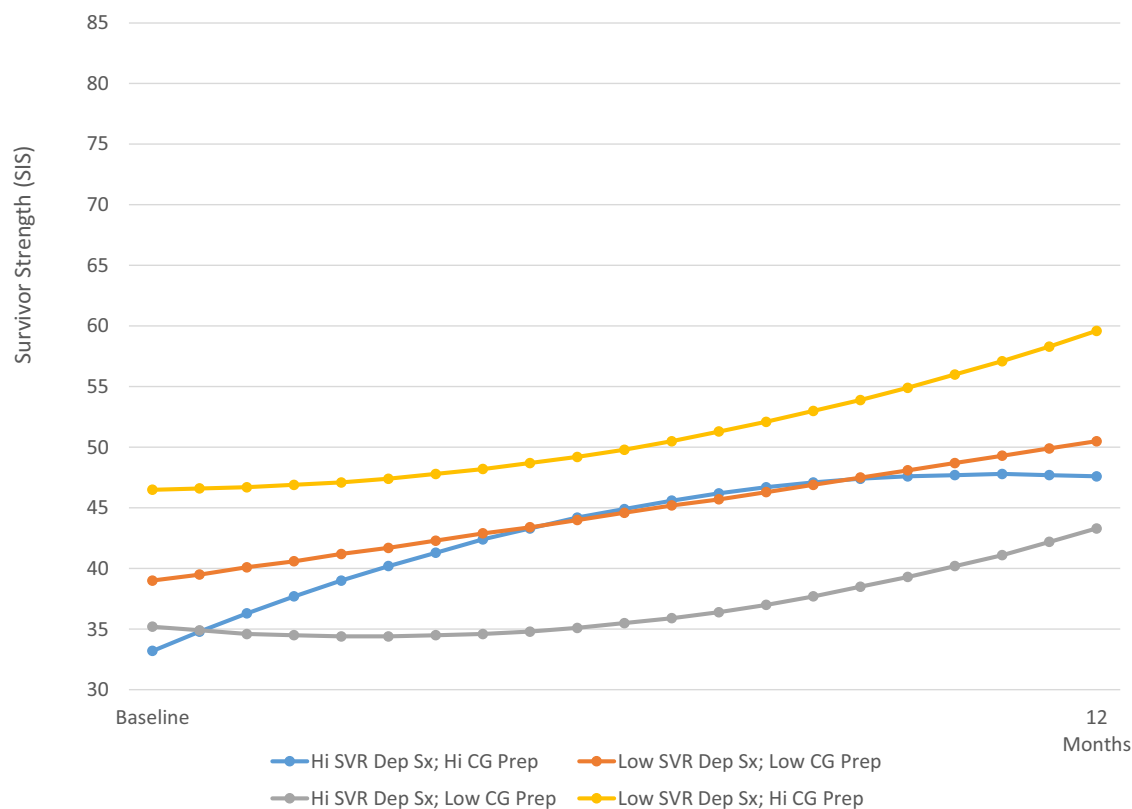


Figure 2. The role of caregiver preparedness between depression and SIS strength dimension.

time. As can be seen in *Figure 2*, for survivors who reported high levels of depressive symptoms, having a caregiver who reported high levels of preparedness was associated with greater improvement in strength than when caregivers reported low levels of preparedness. This demonstrates an important protective role for survivor's rehabilitation over time. In the case of communication, although survivors with high levels of depressive symptoms, who had caregivers with high levels of preparedness appear to have lower communication scores at baseline, their linear change demonstrates more improvement over time than those survivors who had caregivers with low levels of improvement (*Figure 3*). Again, this demonstrates an important protective role of caregiver preparedness over time for the stroke survivor.

In the case of both mobility and ADL/IADL, the significant moderating effect of caregiver preparedness at baseline, appears to be more related to those survivors with low levels of depressive symptoms (*Figures 4 and 5*). In other words, the benefits of having a caregiver with high levels of preparedness for both mobility and ADL/IADL were for those survivors reporting low levels of depressive symptoms rather than high levels of depressive symptoms at baseline.

The protective role of caregiver preparedness on stroke impact

Although we found no significant moderating role for caregiver preparedness on the association between survivor depressive

symptoms and four SIS domains (i.e. memory, emotion, hand function, and participation), higher levels of caregiver preparedness were significantly associated with higher survivor scores of emotion, hand function, and participation at baseline (*Table 3*).

Discussion

This study analysed the moderator role of the caregiver preparedness on the association between stroke survivors' depression and QOL. As observed, the caregiver preparedness moderated the association between stroke survivors' depression and survivor communication, mobility and ADL/IADL at baseline. In addition, we observed a linear change for strength and communication and quadratic change for strength. However, although we found no significant moderating role for caregiver preparedness on the association between survivor depressive symptoms and other SIS domains (i.e. memory, emotion, hand function, and participation), higher levels of caregiver preparedness were significantly associated with higher survivor scores of emotion, hand function, and participation at baseline. In other words, these findings highlighted the importance of caregiver preparedness in the stroke survivors' recovery, because when we have stroke caregiver more prepared, his/her preparedness moderates the impact of stroke survivors' depression on their disease-specific QOL.

At baseline, caregiver preparedness moderated the association between depression and communication, mobility, and ADL/IADL

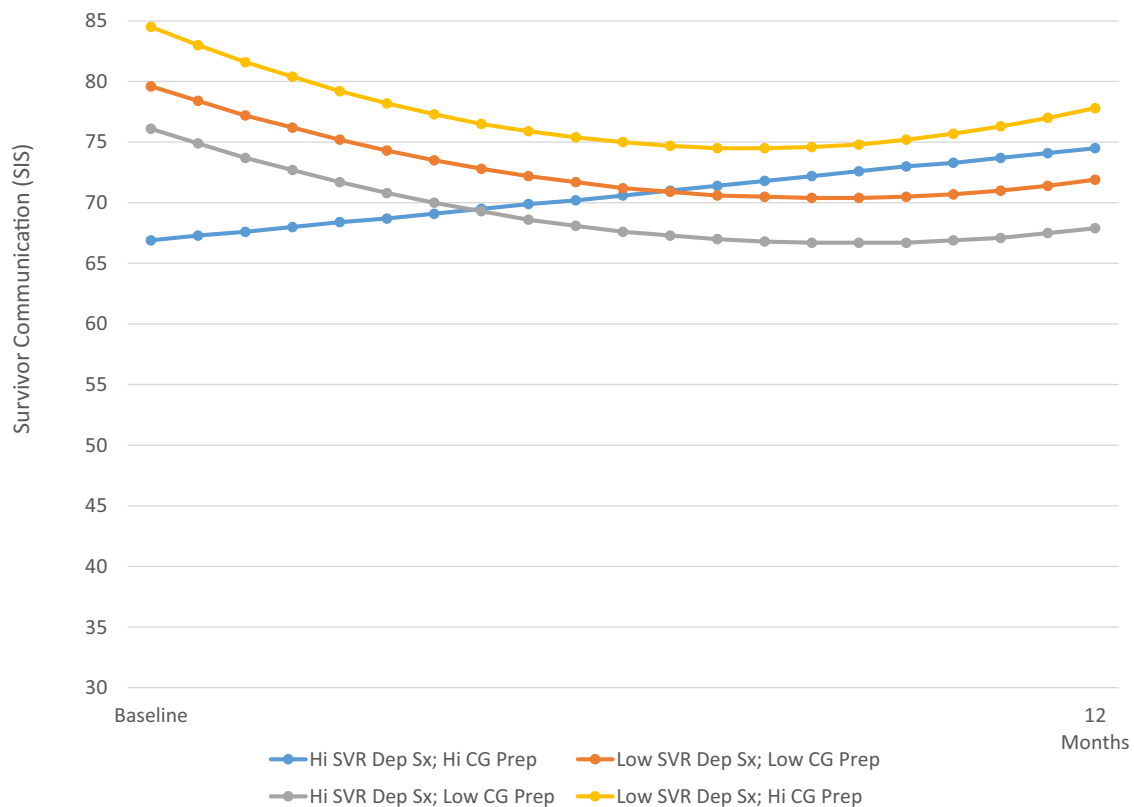


Figure 3. The role of caregiver preparedness between depression and communication SIS dimension.

SIS dimensions. Regarding the communication dimension, we observed that caregiver preparedness moderates the effect of depression on the stroke survivors' QOL. Wittenberg *et al.*²⁴ observed that low-quality communication between family members or the patients' inability to express their emotion could contribute to increase patients' depression. Greater caregiver preparedness could contribute to being better able to understand the survivors' needs. A trained caregiver may have those skills to improve communication with survivors, better perceive their physical and emotional needs. Indeed, in caregiver preparedness, caregivers were asked how much they were able to understand the stroke survivors' psychological needs. Understanding the stroke survivors' psychological needs would mean knowing how to communicate better with stroke survivor. This could explain why, even if the patient is depressed, the caregiver preparedness has a moderating role on stroke survivors' communication. Greater caregiver preparedness may indicate that, when patients are able to better communicate about their issues and even express anger, caregivers may have a better sense of what is needed, reducing the stroke survivors' depression level. Regarding ADL and mobility, instead, post-stroke depression is usually highly negative correlated with mobility. Specifically, the authors showed how stroke survivors with higher post-stroke depression are more likely to have lower ADL and mobility.²⁵ In these associations, the caregiver preparedness plays a crucial role. As described by a meta-analysis,²⁶ stroke survivors who had a trained caregiver and consequently more prepared were more likely to have lower

depression and better physical abilities. Indeed, the authors observed that stroke survivors with stroke caregivers, who received an educational intervention aimed to improve their preparedness, experienced better physical functioning,^{27–29} better memory,^{29,30} and higher QOL.^{30,31} Furthermore, caregivers showed lower depressive symptomatology.^{28,32} Caregiver preparedness was protective for stroke survivors, decreasing their level of depression and increasing their abilities. The first time of stroke survivors' discharge represents the more difficult moment for stroke survivor–caregiver dyads, because it is the time when they truly realize the difficulties that can be encountered with returning home. It is the time when they truly understand what it means to have disabilities and when they learn about the change in their life. All of this increases stroke survivors' depression but having trained caregivers can make these difficulties easier.

In addition, we observed that caregiver preparedness moderated also longitudinally the association between depression and strength. As described by the literature,³³ depression has a negative impact on strength in stroke survivors. For example, a study³⁴ observed that improvements in depression were negatively correlated with strength levels. However, muscular strength is associated with physical activities and exercise habits, which are negatively associated with depression. In this line, the possible effects of muscular strength on depression may be mediated by physical activity, which can partly explain this association.³⁵ Taking into account the significant association between physical activity and the risk of mental illness, it can be

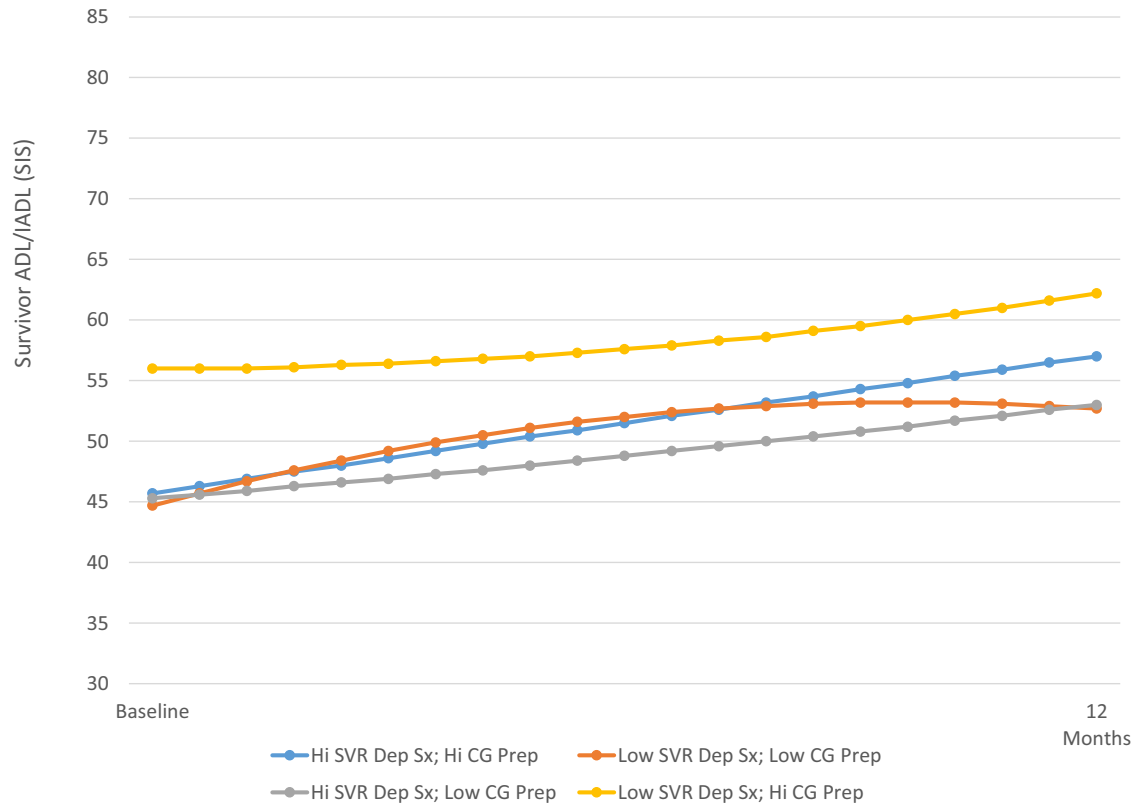


Figure 4. The role of caregiver preparedness between depression and ADL SIS dimension.

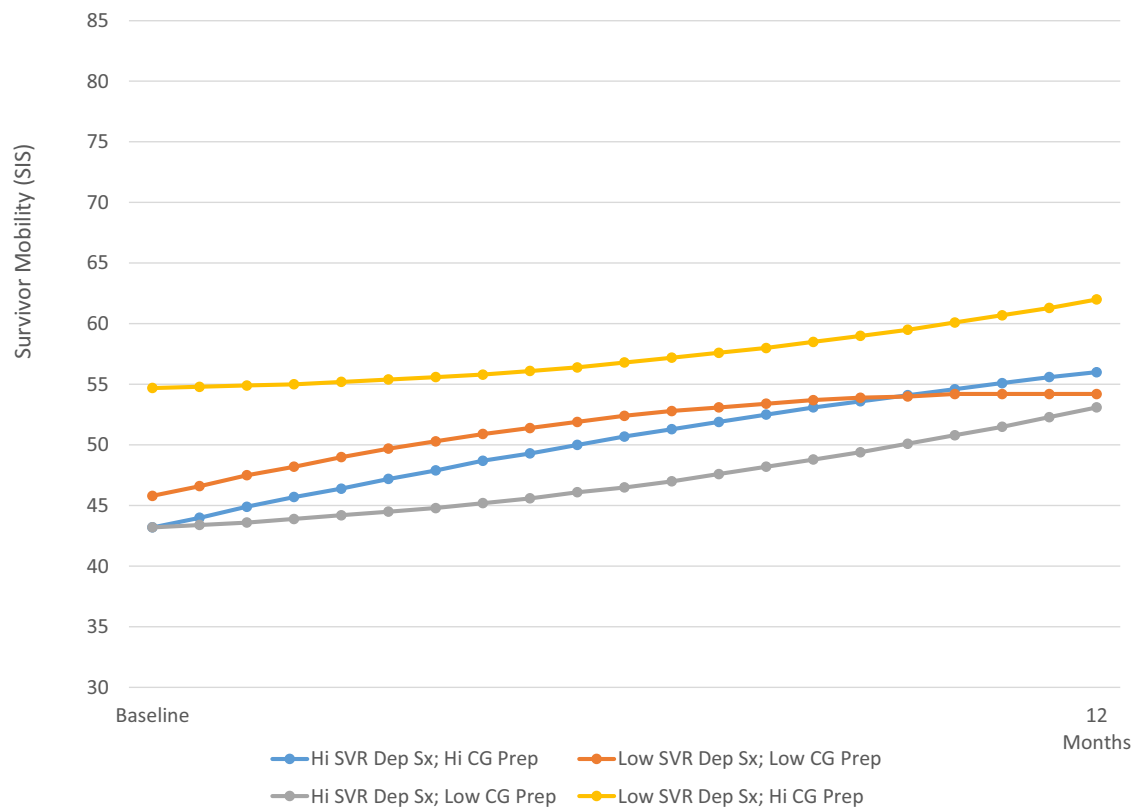


Figure 5. The role of caregiver preparedness between depression and mobility.

hypothesized that caregiver preparedness may have a positive effect on reducing or preventing depression. Indeed, Lutz et al.³⁶ highlighted that having better-prepared caregiver would mean increasing the physical activities in stroke survivors. Increasing physical activities would mean improving stroke survivors' strength and consequently breaking down the depression effect over time.

In addition, although, we did not find a significant moderating role for caregiver preparedness on the association between survivor depressive symptoms and SIS memory, emotion, hand function, and participation domains, the caregiver preparedness had a protective role. Indeed, when caregiver had a higher preparedness, their survivors showed higher memory, emotion, hand function, and participation. However, the mechanism by which caregiver preparedness could improve the survivors' memory, emotion, and social participation is not clear in the literature. Regarding memory, Inns et al.³⁷ observed that higher caregiver preparedness was associated with higher patients' mindfulness and, consequently, with better patient cognitive performance (i.e. memory). Indeed, mindfulness has been associated with cognitive benefits such as improved attention, memory, and executive function in older adults.³⁸ A better-prepared caregiver could increase the stroke survivors' physical activities, increasing neurotrophic factors which promote brain health, with a consequent positive impact on stroke survivors' memory.³⁹ In addition, a better-prepared caregiver may be more able to involve stroke survivors in social life, thus increasing his/her social participation and, consequently, improving their emotions. Maintaining acceptance and equanimity towards experiences in daily life may decrease social threat in ways that increase engagement in social interactions and diminish feelings of loneliness. Furthermore, as observed by the literature, being a strong correlation between caregiver preparedness and mindfulness,³⁷ mindfulness could change caregivers' perceptions of their partners' responsiveness and lead them to seek out more social interactions because they feel more rewarding (and less threatening); it is also possible that developing new habits of relating mindfully with others could attract relationship partners for more interactions.⁴⁰

This study has several implications. First of all, the study highlights the importance to include stroke caregiver in the care process. Although, the importance of including caregivers in a training programme might not appear new, several qualitative studies conducted on stroke caregivers have noted that caregivers usually report being abandoned and inadequately trained. From a clinical point of view, this study observed that better-prepared caregiver could have a positive impact on stroke survivors' outcomes, such as better memory, emotion, hand function, and social participation. In addition, their preparedness could decrease the effect of depression on stroke survivors' specific quality of life in both the short and long terms. Based on these findings, physicians and nurses can develop care models in which caregivers are not excluded from stroke survivors' rehabilitation phase but participate actively in the care process. It is essential to create rehabilitation programmes that increase the skills of caregivers; this would lead to lower levels of re-hospitalization and mortality and improved prognoses for stroke survivors.

Despite its implications, this study has several limitations. Although the sample is large and multicentre, the study was conducted in only one European country (Italy) where caregivers usually are generally not very involved in the rehabilitation programmes. Probably, in other countries where caregivers follow a different caregiving

process, we could observe different results. It would be appropriate to replicate it to compare ethnic, environmental, and national differences. Second, a convenience sample with low to moderate disability was enrolled represented by stroke survivors with no pre-existing severe physical or cognitive impairment, cancer, or severe organ damage. This could be a limitation because patients with less disabilities may also be less depressed and, therefore, more likely to participate in social and physical activities. In addition, we did not analyse if the stroke survivors were taking antidepressant therapies.

Conclusion

Caregiver preparedness represents an important variable that nurses and physicians should consider during the stroke survivors' rehabilitation. Including immediate caregivers in the care process would mean having better-prepared caregivers and consequently more-healthy stroke survivors. A targeted educational intervention designed to improve caregiver preparedness should be applied promptly to the caregiver in the hospital.

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Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

- Katan M, Luft A. Global burden of stroke. *Semin Neurol* 2018;**38**:208–211.
- Virani SS, Alonso A, Benjamin EJ, Bittencourt MS, Callaway CVW, Carson AP, Chamberlain AM, Chang AR, Cheng S, Dellings FN, Djousse L, Elkind MSV, Ferguson JF, Fornage M, Khan SS, Kissela BM, Knutson KL, Kwan TW, Lackland DT, Lewis TT, Lichtman JH, Longenecker CT, Loop MS, Lutsey PL, Martin SS, Matsushita K, Moran AE, Mussolino ME, Perak AM, Rosamond WD, Roth GA, Sampson UKA, Satou GM, Schroeder EB, Shah SH, Shay CM, Spartano NL, Stokes A, Tirschwell DL, VanWagner LB, Tsao CW. Heart disease and stroke statistics – 2020 update: a report from the American heart association. *Circulation* 2020; **141**:e139–e596.
- Wafa HA, Wolfe CDA, Emmett E, Roth GA, Johnson CO, Wang Y. Burden of stroke in Europe: thirty-year projections of incidence, prevalence, deaths, and disability-adjusted life years. *Stroke* 2020;**51**:2418–2427.
- Bennett DA, Krishnamurthi RV, Barker-Collo S, Forouzanfar MH, Naghavi M, Connor M, Lawes CMM, Moran AE, Anderson LM, Roth GA, Mensah GA, Ezzati M, Murray CJL, Feigin VL. The global burden of ischemic stroke: findings of the GBD 2010 study. *Glob Heart* 2014;**9**:107–112.
- Pucciarelli G, Rebora P, Arisido MW, Ausili D, Simeone S, Vellone E, Alvaro R. Direct cost related to stroke: a longitudinal analysis of survivors after discharge from a rehabilitation hospital. *J Cardiovasc Nurs* 2020;**35**:86–94.
- Mandic M. Functional recovery of post stroke patients with hemiparesis after stroke of different aetiology. *Med Pregl* 2012;**65**:158–162.
- Venna VR, Xu Y, Doran SJ, Patrizz A, McCullough LD. Social interaction plays a critical role in neurogenesis and recovery after stroke. *Transl Psychiatry* 2014;**4**:e351.
- Hackett ML, Pickles K. Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *Int J Stroke* 2014;**9**: 1017–1025.

9. Alghwiri AA. The correlation between depression, balance, and physical functioning post stroke. *J Stroke Cerebrovasc Dis* 2016;**25**:475–479.
10. Chen CM, Tsai CC, Chung CY, Chen C-L, Wu KPH, Chen H-C. Potential predictors for health-related quality of life in stroke patients undergoing inpatient rehabilitation. *Health Qual Life Outcomes* 2015;**13**:118.
11. Mores G, Whiteman RM, Ploeg J, Knobl P, Cahn M, Klaponski L, Lindley A, Fisher K. An evaluation of the family informal caregiver stroke self-management program. *Can J Neurol Sci* 2018;**45**:660–668.
12. Araujo O, Lage I, Cabrita J, Teixeira L. Training informal caregivers to care for older people after stroke: a quasi-experimental study. *J Adv Nurs* 2018;**74**:2196–2206.
13. Goudarzi M, Fallahi-Khoshknab M, Dalvandi A, Delbari A, Biglarian A. Effect of tel-nursing on levels of depression and anxiety in caregivers of patients with stroke: a randomized clinical trial. *Iran J Nurs Midwifery Res* 2018;**23**:248–252.
14. Graf R, LeLaurin J, Schmitzberger M, Freytes IM, Orozco T, Dang S, Uphold CR. The stroke caregiving trajectory in relation to caregiver depressive symptoms, burden, and intervention outcomes. *Top Stroke Rehabil* 2017;**24**:488–495.
15. Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology* 2015;**84**:1323–1329.
16. Pucciarelli G, Lyons KS, Petrizzo A, Ambrosca R, Simeone S, Alvaro R, Lee CS, Vellone E. Protective role of caregiver preparedness on the relationship between depression and quality of life in stroke dyads. *Stroke* 2021;**53**:145–153.
17. Savini S, Buck HG, Dickson VV, Simeone S, Pucciarelli G, Fida R, Matarese M, Alvaro R, Vellone E. Quality of life in stroke survivor-caregiver dyads: a new conceptual framework and longitudinal study protocol. *J Adv Nurs* 2015;**71**:676–687.
18. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the hospital anxiety and depression scale. An updated literature review. *J Psychosom Res* 2002;**52**:69–77.
19. Wiglusz MS, Landowski J, Michalak L, Cubala WJ. Validation of the Hospital Anxiety and Depression Scale in patients with epilepsy. *Epilepsy Behav* 2016;**58**:97–101.
20. Iani L, Lauriola M, Costantini M. A confirmatory bifactor analysis of the Hospital Anxiety and Depression Scale in an Italian community sample. *Health Qual Life Outcomes* 2014;**12**:84.
21. Duncan PW, Bode RK, Min Lai S, Perera S. Rasch analysis of a new stroke-specific outcome scale: the stroke impact scale 11. No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit upon the author(s) or upon any organization with which the author(s) is/are associated. *Arch Phys Med Rehabil* 2003;**84**:950–963.
22. Vellone E, Savini S, Fida R, Dickson VV, Melkus GD, Carod-Artal FJ, Rocco G, Alvaro R. Psychometric evaluation of the Stroke Impact Scale 3.0. *J Cardiovasc Nurs* 2015;**30**:229–241.
23. Pucciarelli G, Savini S, Byun E, Simeone S, Barbaranelli C, Vela RJ, Alvaro R, Vellone E. Psychometric properties of the caregiver preparedness scale in caregivers of stroke survivors. *Heart Lung* 2014;**43**:555–560.
24. Wittenberg E, Buller H, Ferrell B, Koczywas M, Borneman T. Understanding family caregiver communication to provide family-centered cancer care. *Semin Oncol Nurs* 2017;**33**:507–516.
25. Paolucci S, Iosa M, Coiro P, Venturiero V, Savo A, De Angelis D, Morone G. Post-stroke depression increases disability more than 15% in ischemic stroke survivors: a case-control study. *Front Neurol* 2019;**10**:926.
26. Pucciarelli G, Lommi M, Magwood GS, Simeone S, Colaceci S, Vellone E, Alvaro R. Effectiveness of dyadic interventions to improve stroke patient-caregiver dyads' outcomes after discharge: a systematic review and meta-analysis study. *Eur J Cardiovasc Nurs* 2021;**20**:14–33.
27. Galvin R, Cusack T, O'Grady E, Murphy TB, Stokes E. Family-mediated exercise intervention (FAME): evaluation of a novel form of exercise delivery after stroke. *Stroke* 2011;**42**:681–686.
28. Marsden D, Quinn R, Pond N, Golledge R, Neilson C, White J, McElduff P, Pollack M. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. *Clin Rehabil* 2010;**24**:328–341.
29. Wang TC, Tsai AC, Wang JY, Lin Y-T, Lin K-L, Chen JJ, Lin BY, Lin TC. Caregiver-mediated intervention can improve physical functional recovery of patients with chronic stroke: a randomized controlled trial. *Neurorehabil Neural Repair* 2015;**29**:3–12.
30. Ostwald SK, Godwin KM, Cron SG, Kelley CP, Hersch G, Davis S. Home-based psychoeducational and mailed information programs for stroke-caregiving dyads post-discharge: a randomized trial. *Disabil Rehabil* 2014;**36**:55–62.
31. Forster A, Young J, Chapman K, Nixon J, Patel A, Holloway I, Mellish K, Anwar S, Breen R, Knapp M, Murray J, Farrin A. Cluster randomized controlled trial: clinical and cost-effectiveness of a system of longer-term stroke care. *Stroke* 2015;**46**:2212–2219.
32. Fens M, van Heugten CM, Beusmans G, Metsmakers J, Kester A, Limburg M. Effect of a stroke-specific follow-up care model on the quality of life of stroke patients and caregivers: a controlled trial. *J Rehabil Med* 2014;**46**:7–15.
33. Marques A, Gomez-Baya D, Peralta M, Frasquillo D, Santos T, Martins J, Ferrari G, Gaspar de Matos M. The effect of muscular strength on depression symptoms in adults: a systematic review and meta-analysis. *Int J Environ Res Public Health* 2020;**17**:5674.
34. Aidar FJ, de Matos DG, de Oliveira RJ, Carneiro AL, Cabral BGDAT, Dantas PMS, Reis VM. Relationship between depression and strength training in survivors of the ischemic stroke. *J Hum Kinet* 2014;**43**:7–15.
35. Almeida OP, Hankey GJ, Yeap BB, Golledge J, Hill KD, Flicker L. Depression among nonfrail old men is associated with reduced physical function and functional capacity after 9 years follow-up: the health in men cohort study. *J Am Med Dir Assoc* 2017;**18**:65–69.
36. Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, Cook C. Improving stroke caregiver readiness for transition from inpatient rehabilitation to home. *Gerontologist* 2017;**57**:880–889.
37. Innis AD, Tolea MI, Galvin JE. The effect of baseline patient and caregiver mindfulness on dementia outcomes. *J Alzheimers Dis* 2021;**79**:1345–1367.
38. Lao SA, Kissane D, Meadows G. Cognitive effects of MBSR/MBCT: a systematic review of neuropsychological outcomes. *Conscious Cogn* 2016;**45**:109–123.
39. Nuzum H, Stickel A, Corona M, Zeller M, Melrose RJ, Wilkins SS. Potential benefits of physical activity in MCI and DEMENTIA. *Behav Neurol* 2020;**2020**:7807856.
40. Khalifian CE, Barry RA. The relation between mindfulness and perceived partner responsiveness during couples' vulnerability discussions. *J Fam Psychol* 2021;**35**:1–10.