PROTOCOL

Quality of life in stroke survivor–caregiver dyads: a new conceptual framework and longitudinal study protocol

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Abstract

Aim. To describe a new conceptual framework and the research protocol of a study designed to examine the quality of life in stroke survivor–caregiver dyads.

Background. Stroke has a significant impact on the patient–caregiver dyad. Few studies have been guided by a specific conceptual framework which considers the interactions among pre-existing situations prior to stroke, the new situation caused by the stroke and the moderating effects of environmental and caregiver-related variables.

Design. Longitudinal study.

Methods. A sample of stroke survivor–caregiver dyads will be enrolled at patient discharge from rehabilitation hospitals and will be surveyed every 3 months for 1-year. Hypotheses generated from the conceptual framework will test predictors, mediators and moderators of stroke survivor and caregiver quality of life from the pre-existing situation prior to the stroke, the new situation mediation poststroke and situation moderators. The study is supported by a grant from the Centre of Excellence for Nursing Scholarship, Rome, December 2013.

Discussion. This study seeks to identify variables in the pre-existing situation prior to the stroke (e.g. living condition), the new situation mediation poststroke (e.g. type of stroke and caregiver burden) as well as situation moderators (e.g. social support) that influence stroke survivor-caregiver dyad's quality of life across the stroke trajectory. Also, the study will inform clinical practice and research by identifying variables that are potentially modifiable and therefore amenable to intervention. The proposed framework will also be helpful for future research focused on stroke survivor–caregiver dyads.

Keywords: conceptual framework, dyad, longitudinal study, nursing, quality of life, stroke, stroke caregiver, stroke survivor, study protocol

Why is this research needed?

- Poor quality of life in stroke caregivers is associated with patient rehospitalization and increased healthcare costs. The study introduces a new theoretically and empirically derived conceptual framework, which predicts quality of life in stroke survivor–caregiver dyad's quality of life.
- The conceptual framework will be tested in a proposed longitudinal study to examine the predictive power of the framework in stroke survivor–caregivers dyad's quality of life at baseline and 3, 6, 9 and 12 months after patients are discharged home.
- The results of this study will also potentially provide evidence for the mechanism by which selected predictors, mediators and moderators affect stroke survivor–caregiver dyads' quality of life to inform future interventions to improve their quality of life.

Introduction

Stroke is a leading cause of death and disability among adults in developed countries (Feigin *et al.* 2014). International studies show a prevalence of stroke from 6·2–13·9% in people over 60 years of age (Go *et al.* 2014) and an incidence per year of 141·3 new cases in men and 94·6 in women per 100·000 among people aged between 65–84 years (European Registers of Stroke I. *et al.* 2009).

Stroke has a significant impact on stroke survivor–caregiver dyads' quality of life (QOL) (Cecil *et al.* 2013, Simeone *et al.* 2014). Approximately 35% of stroke survivors have severe disabilities and limitations in activities of daily living; 30% suffer from depression and cognitive impairment (Chen *et al.* 2010), all factors known to influence QOL negatively. In addition, stroke has a significant impact on caregivers who often exhibit low QOL, high stress, burden, anxiety and depression (Nir *et al.* 2009). Numerous studies have shown that poor QOL in stroke caregivers is associated with the rehospitalization of stroke survivors and increased health costs (Perrin *et al.* 2009, Garcia-Perez *et al.* 2011).

Several studies have been conducted on QOL both for stroke survivors and stroke caregivers (Green & King 2010, McPherson *et al.* 2011), but most of these have used a cross-sectional design limiting the ability to understand the process of the patient's recovery and caregiver's experience, which can change over time (Godwin *et al.* 2013a,b). Also, few longitudinal studies conducted both on stroke survivors and their caregivers have considered the mechanisms of the interactions among pre-existing situation prior to the stroke, the

new situation caused by the stroke and the moderating effects of environmental- and caregiver-related variables. This significant gap in the science may be a result of the limited theoretical work conducted in this population. Further research is needed to examine the patient and caregiver perspective on the stroke experience and the resulting QOL outcomes in these stroke survivor and caregiver dyads.

Conceptual framework and background

The conceptual framework presented in Figure 1 will guide this study and was adapted from McCubbin *et al.* (1983) and Lazarus and Folkman (1984) conceptual models. The conceptual framework of the study was also informed by the extant literature. This literature suggests that QOL in stroke survivor–caregiver dyads is influenced by the pre-existing situation prior to the stroke, the mediation of the new situation poststroke and moderators such as environmental and caregiver-related variables (e.g. continuity of stroke rehabilitation and social support) (Carod-Artal 2012, Ellis *et al.* 2013). The conceptual framework suggests that the pre-existing situation prior to stroke has a direct influence on the new situation poststroke and an indirect influence on the QOL of survivor–caregiver dyads (the outcome of the model). The dyad's pre-existing situation refers to the individual characteristics of stroke survivors and their caregivers as well as the characteristics of their relationship. The new situation is the stroke and related caregiving and this is posited to mediate the relationship between the pre-existing situation and the dyad's QOL. Several situational moderators, such as the amount of social and rehabilitative support available, are hypothesized to influence the relationship between the new situation and the outcomes. As illustrated in the model, QOL outcomes are conceptualized as dyadic outcomes; hence, it is hypothesized that the QOL of stroke survivors and caregivers is interdependent and each influences the other (Baumann *et al.* 2012). We will discuss each concept further in the following sections.

Pre-existing situation prior to stroke

According to the current literature, the pre-existing situations of stroke survivors and their caregivers, including such elements as socio-demographics, living conditions, the affective relationship between the stroke survivor and the caregiver and the stroke survivor's comorbidity, can all influence dyad QOL (Baumann *et al.* 2012).

In stroke survivors, socio-demographic factors that have been found to influence QOL are age, gender, marital status and education. Older age in stroke survivors has been
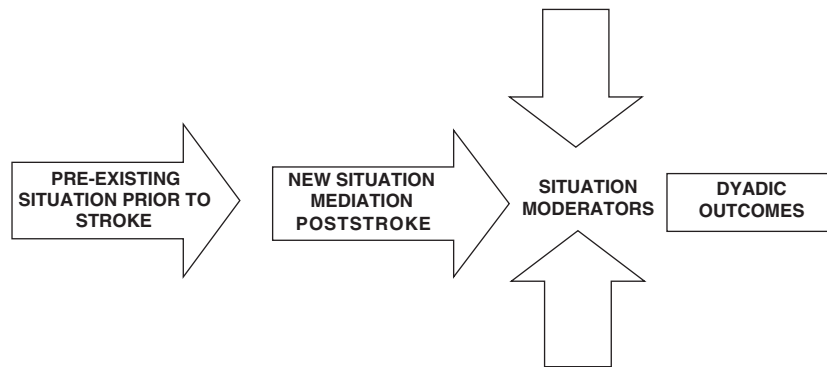
Figure 1 The conceptual framework of the study.

found to be associated with lower physical QOL, but higher emotional QOL (Baumann *et al.* 2012). Baumann *et al.* (2012) reported that female stroke survivors exhibited greater life satisfaction and mental health than male survivors and that life satisfaction was positively correlated with five QOL dimensions: feelings, sleep, emotion, cognition and pain (Baumann *et al.* 2012). The same authors have also found that QOL is better in married stroke survivors than in those who are separated, divorced or widowed (Baumann *et al.* 2012). These findings suggest that the emotional and social aspects of living in partnership are important to subjective well-being. Education is another variable that influences QOL in stroke survivors as it has been found that stroke survivors who are more educated have better coping and better global QOL than those who are less educated (Dayapoglu & Tan 2010).

Similarly for caregivers, the socio-demographic characteristics that can influence QOL include gender, marital status and whether they are living with the patient (Klinedinst *et al.* 2009). Several studies (Aprile *et al.* 2008, Brajkovic *et al.* 2009) have found increased levels of burden and depression among female caregivers compared with male caregivers. In particular, female caregivers were less likely to ask for help and support in patient care and spent more time on caregiving than males even though having a female caregiver was associated with a better QOL for the stroke survivor (Klinedinst *et al.* 2009). Female caregivers who consistently scored low on mental QOL were found to be more likely to be unemployed and reported higher burden scores and a lower overall QOL (White *et al.* 2003). Stroke caregiver's QOL has also been found to be influenced by education (Brajkovic *et al.* 2009).

Living conditions influence the QOL for both stroke survivors and their caregivers. Stroke survivors and caregivers living in urban areas reported better QOL than those living

in rural areas, presumably because they had easier access to social and medical support (Dayapoglu & Tan 2010, Baumann *et al.* 2012).

Another characteristic that can affect QOL for caregivers and survivors is their relationship. Several authors (Dayapoglu & Tan 2010, Delcourt *et al.* 2011) have shown that married stroke survivors and stroke caregivers have a better QOL than those who are unmarried, probably due to better support. Other authors found that mutuality in survivor and caregiver dyad is a positive predictor of their QOL (Ostwald *et al.* 2009b).

Comorbidity in the stroke survivor is associated with both the stroke survivor's and his/her caregiver's QOL. More comorbid conditions in survivors decrease their QOL and increase mortality, especially in females (Icks *et al.* 2012). Conversely, quality of life, well-being and functional ability have been shown to be higher in stroke survivors with no comorbidities especially for male stroke survivors, those who are currently employed and those with higher education levels. In addition, comorbid conditions have a negative impact on the outcomes of patient rehabilitation and social reintegration and increase the caregiver burden (Van Puymbroeck *et al.* 2008, Ellis *et al.* 2013).

New situation mediation poststroke
A stroke is indeed both a new and a sudden situation for the stroke survivor–caregiver dyad. Two groups of variables are associated with this new situation: stroke-related variables and caregiving-related variables. Stroke-related variables can be categorized as type and site of stroke, physical functioning, mood state (anxiety and depression) and stroke complications (e.g. falls). The caregiving-related variables are the burden, anxiety and depression, expenses for care, caregiving duration and time available for caregiving.

The type of stroke has a varying impact on stroke survivor QOL (Cadilhac *et al.* 2010). For example, stroke caused by an intra-cerebral haemorrhage has a deeper impact on QOL than an ischaemia (Cadilhac *et al.* 2010). Also, the site of the brain lesion can have an influence on QOL. It is known that patients with right hemispherical lesions have better functional status than those with a lesion in the left hemisphere of the brain (Dayapoglu & Tan 2010).

Physical functioning is another stroke-related variable influencing stroke survivor QOL. Stroke can limit the activities of daily life (ADL) (Rouillard *et al.* 2012), which can then reduce participation in work, household responsibilities and social and leisure activities. As a result, there may be role changes, social isolation and lower emotional and mental QOL (Rouillard *et al.* 2012).

Depression and anxiety affect the stroke survivor's outcome and recovery including QOL (Kouwenhoven *et al.* 2011). High levels of depression increase the risk of death by more than 10% (Raju *et al.* 2010) and may cause poorer adherence to treatment (Kronish *et al.* 2012) and less autonomy in self-care activities (Korpershoek *et al.* 2011). As a consequence of a stroke, survivors may also experience high levels of anxiety especially during the first weeks following the stroke (D'Aniello *et al.* 2014).

Stroke is associated with numerous complications that can influence QOL. Falls are very common among stroke rehabilitation patients. It has been estimated that between 14–65% of stroke survivors fall at least once during hospitalization (Weerdesteyn *et al.* 2008) and up to 73% of patients fall during the first 6 months after discharge (Batchelor *et al.* 2010). Falls adversely affect the stroke survivors' QOL and increase their risk of morbidity and mortality (Wagner *et al.* 2009).

Stroke caregiving is particularly burdensome for women who experience depression, anxiety and burden (Carod-Artal 2009, Vincent *et al.* 2009). Often these variables are interrelated. Burden in female caregivers increases with the length of time spent in caregiving. Caregiving burden is exacerbated by the lack of preparation for caregiving (Visser-Meily *et al.* 2005). Studies (Visser-Meily *et al.* 2005) have shown that caregiver burden is related to a caregiver's depressive symptoms, to the survivor's activities of daily living (ADL) and to disharmony in the relationship with the stroke survivor. Caregiver burden influences caregiver QOL and may change over time, but the change patterns are still unclear in the literature (Vincent *et al.* 2009).

Literature has shown that decreased psychological QOL in caregivers is correlated with the number of hours spent in caregiving. That is because an increased level of involvement or the number of hours spent in caregiving often results in lower participation in social activities, as well as increased frustration and depression (Lurbe-Puerto *et al.* 2012).

After a stroke, caregivers may experience many direct and indirect expenses due to caregiving: they may need to buy equipment for patient care or they may have to give up work. It has been shown that additional expenses worsen stroke caregiver QOL (Sreedharan *et al.* 2013).

Caregiving duration is another caregiving-related variable that influences caregiver QOL. In general, caregiver QOL is lower at the beginning of the caregiving experience, but tends to improve over time (Nir *et al.* 2009). However, stroke caregiver QOL is significantly lower than in the general population (Visser-Meily *et al.* 2008).

Situation moderators

Moderators are variables that affect the association between an independent and a dependent variable. Specifically, a moderator is an independent variable that affects the strength, either by inhibiting or enhancing and/or directing the association between another independent variable and an outcome variable (Levy *et al.* 2011). One group of moderators that can affect the QOL outcomes is included in the conceptual framework of this study: namely, environmental- and caregiver-related variables. These variables include social support, the continuity of stroke rehabilitation and caregiving preparation.

In the environmental- and caregiver-related factors, social support is a powerful moderator in stroke survivor QOL (Lee *et al.* 2010). In fact, patients who receive support from family, even patients who are more depressed or less educated, report better QOL than those who do not have social support (Lee *et al.* 2010). Lack of social support is a predictor of lower emotional QOL even among stroke survivors who are more independent in ADL (Kruithof *et al.* 2013). Taylor-Piliae *et al.* (2013) found that social support predicts better physical functioning, greater vitality and less depression in stroke patients.

The continuity of stroke rehabilitation after discharge from the rehabilitation hospital was found to influence QOL for both stroke survivors and their caregivers. Among stroke patients, the continuity of rehabilitation was associated with a significant reduction of dependence (Aprile *et al.* 2008, Shyu *et al.* 2009).

Another variable that moderates the relationship between predictors and outcomes for the stroke survivor-caregiver dyad is caregiver preparation. Ostwald *et al.* (2009b) and Grant *et al.* (2013) have shown that low preparedness is a

significant predictor of caregiver stress, as well as a predictor of negative mood and depression among caregivers.

The study

Aims

The aim of this study is to describe stroke survivor–caregiver dyad's QOL at discharge from rehabilitation hospital and at 3, 6, 9 and 12 months later and to examine how QOL changes over time by looking at the effect of the pre-existing situation prior to the stroke, the new situation mediation poststroke and any moderation caused by environmental- and caregiver-related variables.

Hypotheses

Three hypotheses were generated from the conceptual framework:

- Dyadic characteristics (pre-existing situation prior to the stroke) predict stroke survivor–caregiver dyad's QOL (dyadic outcomes);
- Stroke-related variables and caregiving-related variables (the new situation mediation poststroke) mediate the relationship between the dyadic characteristics (pre-existing situation prior to the stroke) and stroke survivor–caregiver QOL (dyadic outcomes);
- Environmental- and caregiver-related variables (situation moderators) moderate the relationship among dyadic characteristics (pre-existing situation prior to the stroke), stroke-related variables and caregiving-related variables (new situation mediation poststroke) and stroke survivor–caregiver QOL (dyadic outcomes).

Design/methodology

A longitudinal design will be used. As described above, variables in the conceptual framework, (e.g. caregiver burden) are likely to vary over time due to changes caused by the stroke survivor's recovery and skills acquired in caregiving. For these reasons, a longitudinal design is appropriate.

Sample/participants

A convenience sample of stroke survivor–caregiver dyads will be enrolled. Stroke survivor inclusion criteria are: (1) a diagnosis of stroke; (2) discharge from a rehabilitation hospital; and (3) the willingness to provide written consent to participate in the study. Stroke survivors will be excluded if they have: (1) severe and pre-existing psychiatric or physical/motor deficits (e.g. dementia, Multiple Sclerosis); (2) a

previous stroke, aphasia or reduced level of consciousness; (3) a cancer (either terminal or under active treatment); (4) a severe organ failure condition that is known to be associated with poor QOL. Inclusion criteria for stroke caregivers are the following: (1) being identified as the main caregiver by the patient without being paid; (2) the stroke survivor's agreement to participate in the study; and (3) the willingness to provide written consent to participate. If one member of the dyad cannot be included in the study, both stroke survivor and caregiver will be excluded.

Sample size

Because we will examine the model shown in Figure 1 with structural equation model technique, a large sample is required. In accordance with Kline (2011), a sample of minimum 200 patient–caregiver dyads will be necessary.

Data collection

Intervals of measurement have been planned consistent with the international literature as measured at baseline (time 0, coinciding with the discharge of patients from rehabilitation hospitals) and then 3, 6, 9 and 12 months later (Godwin *et al.* 2013b, Mayo *et al.* 2013).

Guided by the conceptual framework, several instruments will be used to collect the data about pre-existing situation prior to stroke, the new situation mediation poststroke, the situation moderators and dyadic outcomes (Table 1). The pre-existing situation prior to stroke has been operationalized as dyad characteristics and will be measured using two socio-demographic questionnaires developed to collect dyad data such as age, gender, marital status, employment, education, income, living conditions and family situation, both for the patient and the caregiver, the Mutuality Scale (Archbold *et al.* 1990) and the Modified Charlson Comorbidity Index (Goldstein *et al.* 2004).

The Mutuality Scale (MS) (Archbold *et al.* 1990) consists of 15 items that measure mutuality defined as the positive quality of the relationship between a caregiver and a care receiver. There are two versions of the scale: the patient version and the caregiver version. Each item uses a 5-point Likert scale from 0 ('nothing')–4 ('very much'). The total scale score ranges from 0–60. Higher scores indicate higher mutuality. The MS has been used in several studies (Tanji *et al.* 2008, Ostwald *et al.* 2009b) and has demonstrated adequate validity and reliability (Archbold *et al.* 1990).

The Modified Charlson Comorbidity Index (MCCI) (Goldstein *et al.* 2004) assesses the presence of 16 comorbid conditions, which are weighted with a score from 1 (e.g. diabetes without complications)–6 (e.g. cancer or AIDS).

The total score ranges from 0–31, with higher scores meaning higher comorbidity. This index has been used extensively in stroke studies (Bushnell *et al.* 2008) and, compared with other comorbidity indices, has been found to be more accurate in predicting functional outcomes after a stroke (Tessier *et al.* 2008).

The new situation mediation poststroke has been operationalized as stroke-related variables and caregiving-related variables. Stroke-related variables will be evaluated using a clinical questionnaire, the Barthel Index (Mahoney & Barthel 1965), the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983) and the living and caring questionnaire. Caregiving-related variables will be measured with the HADS, the Caregiver Burden Inventory (CBI) (Novak & Guest 1989) and relevant questions embedded in the socio-demographic questionnaire that record expenses for care borne by the caregiver and hours and duration of caregiving.

The clinical questionnaire and the living and caring questionnaire are two investigator-developed tools that will be used to collect clinical data about type and site of stroke, healthcare costs and complications (e.g. falls).

The Barthel Index (BI) (Mahoney & Barthel 1965) is a widely used valid and reliable scale that measures physical functioning in 10 activities of daily living (ADL) (e.g. mobility). Score ranges from 0–100, where a higher score means greater independence.

The HADS (Zigmond & Snaith 1983) is a 14-item tool that investigates anxiety and depression (7 items for each). Each subscale score ranges from 0–21: a higher score corresponds to higher levels of anxiety and depression. The HADS is widely used on stroke patients (Sagen *et al.* 2010). Validity and reliability of the HADS are adequate (Bjelland *et al.* 2002).

The Caregiver Burden Inventory (CBI) (Novak & Guest 1989) assesses the caregiver's burden. It consists of 24 items, which use a 4-point Likert scale. Higher scores indicate a greater burden (Novak & Guest 1989). Novak & Guest (Novak & Guest 1989) reported Cronbach's alphas for subscales ranging from 0·76–0·96. The CBI has been also used on Italian caregivers (D'Amelio *et al.* 2009, Luchetti *et al.* 2009).

The situation moderators have been operationalized as environmental- and caregiver-related variables and will be evaluated with the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet *et al.* 1990), the Caregiving Preparedness Scale (CPS) (Archbold *et al.* 1990) and with information collected with the socio-demographic questionnaire about continuity of stroke rehabilitation.

The MSPSS (Zimet *et al.* 1990) measures the perceived support received from family members, friends and significant persons. It consists of 12 items, which use a 7-point Likert scale from 'strongly disagree' to 'strongly agree'. The score ranges from 0–84 with higher score meaning the perception of greater social support. This scale has been used in several studies on caregiving (Yu *et al.* 2013) and has adequate internal consistency reliability. It has been used also in an Italian study resulting in adequate validity and reliability (Cicero *et al.* 2009).

The Caregiver Preparedness Scale (CPS) (Archbold *et al.* 1990) measures the preparedness of the caregiver in caregiving activities (e.g. physical care). It is composed of eight items, which use a 5-point Likert scale from 'not at all prepared' to 'very well prepared'. The score ranges from 0–40: higher score means a better preparedness for caregiving. The CPS has been used in several studies and in stroke caregivers (Ostwald *et al.* 2009a, Owolabi 2010) and has adequate validity and reliability (Archbold *et al.* 1990).

The dyadic outcomes have been operationalized as the QOL for the stroke survivor-caregiver dyads and will be measured by: the Stroke Impact Scale 3.0 (SIS 3.0) (Duncan *et al.* 1999, Vellone *et al.* 2014), the World Health Organization Quality of Life-Brief (WHOQOL-BRIEF) (WHOQOL Group 1998) and the World Health Organization Quality of Life-Spiritual, Religiousness and Personal Beliefs (WHOQOL-SRPB) (WHOQOL-SRPB Group 2006).

The SIS 3.0 (Duncan *et al.* 2003, Vellone *et al.* 2014) is a valid and reliable multidimensional and disease-specific instrument to measure QOL in patients with stroke. It is composed of 59 items, which use a 5-point Likert scale. The SIS 3.0 also has a 0–100 VAS item that measures the perceived global recovery from stroke. The SIS 3.0 has a standardized score from 0–100, where higher scores mean a better quality of life. This scale will be used only for patients.

The WHOQOL-BRIEF (WHOQOL Group 1998) is a 26-item instrument that measures four domains of QOL: physical, psychological, social and environmental. Each item uses a 5-point Likert scale and a standardized score from 0–100 can be computed per each scale with higher scores meaning better QOL. Concurrent validity of the WHOQOL-BRIEF has been demonstrated (WHOQOL Group 1998). The Italian version of the WHOQOL-BRIEF showed adequate validity and reliability (De Girolamo *et al.* 2000).

The WHOQOL-SRPB (WHOQOL-SRPB Group 2006) consists of 32 questions measuring additional domains of QOL related to spirituality, religion and beliefs. The eight domains are: spiritual connection, meaning and purpose in life, experience of awe and wonder, wholeness and integration, spiritual strength, inner peace, hope and optimism and faith (Giovagnoli *et al.* 2006). Validity and reliability of this instrument are supportive (Panzini *et al.* 2011). This

Table 1 Variables and instruments that will be used to collect the data corresponding to the conceptual framework concepts.

Conceptual framework concepts	Operationalized as:	Measured by:	Individual measures: Stroke survivor	Stroke caregiver	Measured at (months):
Pre-existing situation prior to stroke	Dyadic characteristics Stroke survivor				
	Socio-demographic	Socio-demographic questionnaire	X		0
	Living conditions	Socio-demographic questionnaire	X		0
	Relationship	Mutuality scale	X		0
	Stroke survivor's comorbidity	Modified Charlson Comorbidity Index	X		0
	Stroke caregiver				
	Socio-demographic	Socio-demographic questionnaire		X	0
	Living conditions	Socio-demographic questionnaire		X	0
	Relationship	Mutuality scale	X	X	0
New situation mediation poststroke	Stroke-related variables				
	Type and site of stroke	Clinical questionnaire	X		0
	Physical functioning	Barthel index	X		0, 3, 6, 9, 12
	Mood state (depression and anxiety)	HADS	X		0, 3, 6, 9, 12
	Stroke complications (e.g. falls)	Living and caring questionnaire	X		0, 3, 6, 9, 12
	Caregiving-related variables				
	Depression and anxiety	HADS		X	0, 3, 6, 9, 12
	Burden	Caregiving Burden Inventory		X	0, 3, 6, 9, 12
	Time for caregiving	Socio-demographic questionnaire		X	0, 3, 6, 9, 12
	Expenses for care	Socio-demographic questionnaire		X	0, 3, 6, 9, 12
	Caregiving duration	Socio-demographic questionnaire		X	0, 3, 6, 9, 12
Situation moderators	Environmental- and caregiver-related variables				
	Social support	MSPSS		X	0, 3, 6, 9, 12
	Continuity of stroke rehabilitation	Socio-demographic questionnaire	X		0, 3, 6, 9, 12
	Caregiving preparation	Caregiving Preparedness Scale		X	0, 3, 6, 9, 12
Dyadic outcomes	Quality of life				
	Stroke survivor QOL	SIS 3.0	X		0, 3, 6, 9, 12
		WHOQOL-Brief	X	X	0, 3, 6, 9, 12
	Stroke caregiver QOL	WHOQOL-SRPB	X	X	0, 3, 6, 9, 12

QOL = Quality of life; HADS = Hospital Anxiety and Depression Scale; MSPSS = Multidimensional Scale of Perceived Social Support; SIS = Stroke Impact Scale; WHOQOL-Brief = World Heart Organization Quality of Life-Brief; WHOQOL-SRPB = World Heart Organization Quality of Life-Spiritual Religious and Persona Beliefs

instrument will be used both for stroke survivors and their caregivers.

Patients and caregivers will be approached for enrolment by trained research assistants at the time of patient discharge from rehabilitation hospitals. After the aims of the study have been explained, patients and caregivers willing to participate will sign the informed consent form and will then be interviewed to collect baseline data. In addition, patients' medical records will be reviewed to collect the clinical variables considered in the study (e.g. type and site

of stroke). As it is the intention of the study to examine changes over time, data collection will be repeated at 3, 6, 9 and 12 months after enrolment in the study.

Data analysis

Descriptive statistics (mean, standard deviation, median, interquartile range, frequencies) will be used to summarize the socio-demographic and clinical data and the scale scores. Pearson and Spearman correlations will be used to

identify which variables will be correlated with dyad QOL. Multiple linear regression will also be used to identify predictors of the QOL for stroke survivor-caregiver dyads. The actor-partner interdependence model (APIM) will be used to analyse the dyadic data, as this approach allows investigators to evaluate the influence of partners on each other (Ridker *et al.* 2000). In APIM, the actor effect is the influence of a person's emotions on himself or herself (e.g. the effect of depression on QOL). The partner effect is the impact of the person's emotions on his or her partner (e.g. the effect of depression in the person on the partner's QOL).The APIM will be used as the dyadic analytical procedure to test how some variables in stroke survivors (e.g. depression) will affect the same variables in their caregivers. Structural equation modelling procedures will be used to test the full model outlined in Figure 1. Specifically, both cross-lagged and growth curve models will be used to examine changes in the study variables, its predictors and outcomes. Multi-group analysis will be used to test the effect of moderators (e.g. social support in dyads with high and low QOL) (Baron & Kenny 1986).

Ethical considerations

The study has been approved by the ethical committee of the study institution in January 2014 and is in keeping with the Declaration of Helsinki. Stroke survivor–caregiver dyads will be enrolled on voluntary basis. Before data collection, all study participants will receive information about the study and that their data will be confidential and will be stored in a safe place. The signed informed consent will be obtained by both members of the dyads before proceeding with data collection. Participants will be guaranteed that study results will be published in aggregated form, not allowing the identification of participants. Also, patients and caregivers will be informed that they will have the right to withdraw from the study whenever they want. Research assistants will be trained to respect patients and caregiver time during data collection; thus, if they see that patients and caregivers become tired during data collection, they will offer a pause.

Validity and reliability/rigour

We will use for the study instruments that have been already tested for validity and reliability. For the tools developed by the research team, such as the socio-demographic questionnaires for patient and caregiver, the clinical questionnaire and the living and caring questionnaire, their content validity has been evaluated by a group of experts. For these tools, we will test also their inter-rater reliability.

Discussion

This study will provide a description of stroke survivor–caregiver dyad QOL within the first year after a stroke including patterns of QOL over time. The study will also identify predictors, mediators and moderators of QOL for stroke survivor–caregivers dyads as defined in the conceptual framework developed for this study. The longitudinal approach is a powerful method that will examine how the independent variables and dyad outcomes change over time.

The conceptual framework introduced in this paper for examining QOL in both stroke survivors and their caregivers has the potential to provide important information pertinent to the care of stroke survivor–caregiver dyad across the stroke trajectory. Findings are expected to inform clinical practice by identifying the predictors of dyad QOL that are present in the pre-existing situation prior to stroke and the new situation poststroke. Understanding how environmental-related variables moderate dyadic QOL will allow providers to implement a plan of care focused on the needs of the stroke survivor–caregiver dyad.

In addition, this study has been designed with a conceptual framework that can be used by rehabilitation nurses to promote dyadic QOL. Moreover, the results of this study will potentially have important implications for caregiver education including ensuring adequate social support. Understanding the relationship of stroke-related variables such as the type and site of stroke, physical functioning and stroke complications together with caregiver-related variables such as burden, expenses for care and caregiving duration can help prepare caregivers. Nurses play an important role in assessing the support systems available to stroke survivors. Understanding the complexity of the dyadic relationship can help to develop a plan of care and effective recovery strategy that will deal positively with the negative effects of stroke and reinforce the dyad relationship.

Finally, this study is expected to provide much needed evidence to make institutions aware of the potential difficulties experienced by stroke survivors and their caregivers. If the hypotheses are supported, the implications for transitions in care include strengthening the network of continuity of care between rehabilitation facilities and homecare to ensure that stroke survivor-caregiver dyads have adequate emotional and tangible support throughout the recovery period.

Limitations

As this study will be conducted in Italy, the results should be generalized with caution in other countries due to potential cultural differences. Also, this study will be conducted

in community settings after patients are discharged home, hence results cannot be generalized to the acute or the rehabilitation phases of the stroke during hospitalization.

This study will use a longitudinal design, which means that patient and caregiver dropout could be another potential limitation. To prevent dropout and to minimize inconvenience for patients and caregivers, all data collection after the baseline will be carried out at the home of the patient and caregiver.

Conclusion

Because of the ageing of the population, more people in the future will be affected by stroke. This increase in stroke prevalence and incidence represents a burden for the healthcare system, but also a burden for caregivers, who will have the responsibility of caring for the patient when he or she is at home. The dyadic approach guided by a specific conceptual framework developed in this study represents an opportunity to consider the stroke not only as a patient event but also as a dyadic event for patients and their caregivers.

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Conflict of interest

The authors declare that they have no conflict of interest.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the IC-MJE (http://www.icmje.org/ethical_1author.html)]:

- they have made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- have been instrumental in drafting the article or revising it critically for important intellectual content.

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