

# Working-Age Caregivers of Stroke Survivors: Needs, Concerns, and Quality of Life

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## Abstract

**Purpose:** The purpose of this study was to characterize the unmet needs and concerns of working-age caregivers of stroke survivors and to explore the relationships between these unmet needs and concerns and factors such as stroke survivor functional independence, caregiver strain, caregiver self-efficacy, caregiver perceived social support, and caregiver quality of life (QoL).

**Design:** Cross-sectional descriptive design was used in this study.

**Methods:** Participants ( $N = 103$ ) completed an online survey. Descriptive statistics, bivariate Pearson correlation, and linear regression analysis was performed.

**Results:** Negative correlations were found between caregiver needs and concerns and both stroke survivor functional independence and caregiver self-efficacy. Positive correlations were identified between caregiver needs and concerns and caregiver strain. In multiple regression models, stroke survivor functional independence, caregiver self-efficacy, race, and gender were statistically significantly associated with caregiver QoL.

**Clinical Relevance to the Practice of Rehabilitation Nursing:** Results of this study can inform nurses as they collaborate with informal caregivers and researchers in optimizing the rehabilitation and discharge process and aiding in the support of caregiver QoL.

**Conclusion:** Working-age caregivers of stroke survivors expressed many needs and concerns. These needs, along with other factors, can affect outcomes including QoL in caregivers and stroke survivors.

**Keywords:** Stroke; caregiver; quality of life; working age.

There are approximately 53 million informal caregivers—family or friends who provide care to individuals with illness and disability outside of healthcare institutions without payment—currently in the United States (National Alliance for Caregiving & AARP, 2020). This number will continue to increase as the U.S. population ages, resulting in a greater number of individuals needing care by 2050 (Longacre et al., 2017; Mudrazija, 2019). Working-age caregivers account for 82% of informal caregivers and tend to face more challenges with work, finances, retirement, and

child-rearing and tend to have fewer coping strategies and fewer resource reserves than older caregivers (Bakas et al., 2002; Longacre et al., 2017; National Alliance for Caregiving & AARP, 2020). Many working-age caregivers find it necessary to either quit their job or reduce their work hours, which negatively affects their financial and professional health (Hoffman & Mendez-Luck, 2011; Kimura et al., 2015). The stress related to caregiving may lead to a future generation of care recipients entering old age in worse health and with lower retirement savings than the preceding generation (Kimura et al., 2015).

Stroke often results in serious long-term disability leading to the need for assistance from caregivers who play an important role in the health and well-being of stroke survivors (Harrison et al., 2017; Pucciarelli et al., 2018). Informal caregivers are an essential component of stroke survivor care, yet they are at risk for poorer outcomes because of their own unmet needs. Many informal caregivers report feeling isolated and abandoned when the stroke survivor for whom they provide care transitions from the hospital to home, and they begin to recognize a lack of personal resources such as knowledge, self-efficacy, and support to cope with their new role (Harrison et al., 2017; Markoulakis

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et al., 2018). Caregivers of stroke survivors express needs for information; needs for training in all aspects of care for the stroke survivor; and concerns related to their personal response to their new role as caregiver (Bakas et al., 2002). Direct links have been discovered between stroke survivors' health outcomes and caregiver burden, quality of life (QoL), anxiety, and depression (Lutz et al., 2011; Pucciarelli et al., 2018). Although a substantial body of research literature on stroke caregiving exists and despite findings that stroke caregiver needs and concerns vary by age, stroke caregiver research has focused on broad age groups ranging from 21 to 93 years of age (Andrades-González et al., 2021; Panzeri et al., 2019). This creates a notable research gap in that the specific needs of working-age (18–64 years) stroke caregivers have not been adequately explored.

To address these gaps in knowledge, the purpose of this study was to characterize unmet needs and concerns, caregiver self-efficacy, social support, and QoL of working-age caregivers of stroke survivors through a cross-sectional descriptive online survey using validated measures. The study also explored the relationships between these unmet needs and concerns and factors such as stroke survivor functional independence, caregiver strain, caregiver self-efficacy, caregiver perceived social support, and caregiver QoL.

### Theoretical Model

Quality of life (QoL) is defined as “an individual’s perception of their position in life in the context of their culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns” (The WHOQOL Group, 1995). The model of QoL for family caregivers of stroke survivors developed by White et al. (2004) and further informed by Rose, Newman, Magwood, et al. (2022) provided the theoretical framework for this study. The updated model proposes direct relationships between the caregiving situation (stroke survivor’s functional disability, behavior/mood disturbances, cognitive/communication impairment, survivor characteristics, time spent in daily care, and duration of care), caregiver factors (sociodemographics, health, mastery/burden, role interference, and coping styles), environmental factors (social relationships, relationship with the stroke survivor, healthcare resources, financial resources, and training), and the caregiver’s QoL (Rose, Newman, Magwood, et al., 2022). The model also proposes indirect relationships between the caregiving situation and both caregiver and environmental factors as well as between environmental factors and caregiver factors. This model guided the selection of concepts, operationalization of variables for measurement, choice of appropriate instruments, and exploration of the theoretical relationships between variables.

### Methods

A cross-sectional descriptive design using online survey methods was used in this study. The study was designed and reported using the Checklist for Reporting Results of Internet E-Surveys (Eysenbach, 2004).

### Sample

The sample population was working-age caregivers of stroke survivors. Inclusion criteria were being a family member or friend who was providing unpaid care for a stroke survivor, being between the ages of 18 and 64 years, and being able to read and understand English. The exclusion criterion was lack of access to the online survey platform. A minimum sample size of 93 respondents was targeted with a 95% confidence level and a margin of error of 10 for this exploratory study based on an online sample size calculator (Creative Research Systems, n.d.).

### Ethical Considerations

This study was approved by the Medical University of South Carolina Institutional Review Board as Exempt Category 2, which did not require a formal informed consent process. A statement of research at the beginning of the online survey included all elements of informed consent. After reviewing the statement of research, participants could choose “agree” to proceed with screening questions or “disagree” to exit the survey. Participants completed a self-screening survey to determine whether the eligibility criteria were met. If the participant met the inclusion criteria, they were offered the option to proceed to the survey.

### Measures

The online survey was designed using multiple instruments. Each instrument was chosen to measure the variables and constructs identified using the QoL model for informal caregivers of stroke survivors. The survey was pretested for readability with an estimated completion time of 20–30 minutes.

### Sociodemographic Questionnaire

Sociodemographic data were collected using a principal investigator-developed instrument. Demographic data included age, gender, race, ethnicity, marital status, children living at home, relationship with the survivor, and duration of care. Socioeconomic data included education, occupational status, income, medical insurance status, wealth, home type, and transportation.

### Caregiver Needs and Concerns Checklist

Participants’ unmet needs and concerns were measured using the Caregiver Needs and Concerns Checklist (CNCC), a

self-administered questionnaire consisting of 32 items divided into five domains: information (nine items), emotions and behaviors (seven items), physical care (five items), instrumental care (four items), and personal responses to caregiving (seven items; Bakas et al., 2002). Participants could check which items they felt were needs or concerns for them personally. The responses were coded as “0” for no and “1” for yes. A domain score was calculated by adding all individual items within that domain. A total score was obtained by adding the five domain scores, with a higher score indicating a greater number of unmet needs and concerns (Bakas et al., 2002). The CNCC was developed for stroke caregivers; however, psychometric testing has not been reported (Bakas et al., 2002).

### Barthel Index

Stroke survivor functional independence was measured using the Barthel index (BI; Duffy et al., 2013). The BI is a 10-item measure of activities of daily living. The BI has excellent interrater reliability (KW = 0.93, 95% confidence interval [0.90, 0.96]) with standard administration after stroke (Duffy et al., 2013).

### Revised Scale for Caregiver Self-Efficacy

Caregiver self-efficacy was measured using the Revised Scale for Caregiver Self-Efficacy (RSCSE), which consists of 15 items divided into three sections: obtaining respite (five items), responding to disruptive patient behaviors (five items), and controlling upsetting thoughts about caregiving (five items; Steffen et al., 2002). The instrument uses a 0–100 degree of confidence scale (Steffen et al., 2002). A total score was calculated using the three domain scores composed of the sum of all items within that domain. The RSCSE validity and reliability studies included family caregivers of older adults with cognitive impairment and reported Cronbach’s alpha between .79 and .91 (Steffen et al., 2002). This instrument has also been used with patients (including stroke survivors) and caregivers in a neuroscience intensive care unit (Shaffer et al., 2016).

### Modified Caregiver Strain Index

Caregiver strain was measured using the modified caregiver strain index (MCSI), a self-administered questionnaire with 13 items that measures caregiver strain (Onega, 2013). The scoring is based on a 3-point Likert scale where each “yes” and “sometimes” answer receives 2 points and 1 point, respectively, and a “no” receives 0 points (Onega, 2013). A total score was obtained by adding all item scores together, with a higher score indicating higher caregiver strain (Onega, 2013). The MCSI has been used in stroke caregiver research including studies of perceived burden and stress with test-retest reliability of .88 and internal reliability coefficient

of .09 (Ferguson et al., 2020; Onega, 2013; Serfontein et al., 2019).

### Multidimensional Scale of Perceived Social Support

The caregiver’s perceived social support was measured using the 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1990). The scoring is based on a 7-point Likert scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*), with a higher score indicating higher levels of social support (Zimet et al., 1990). A mean score was obtained for each of the subscales and the total scale (Zimet et al., 1990). MSPSS has been used to measure social support of stroke caregivers with reported Cronbach’s alpha between .81 and .98 (Long et al., 2019; Marima et al., 2019; Zimet et al., 1990).

### Bakas Caregiving Outcomes Scale

The Bakas Caregiving Outcomes Scale (BCOS) is a self-administered 15-item questionnaire that is used to measure caregiver QoL (Bakas et al., 2006.) It uses a 7-point Likert scale ranging from –3 (changed for the worst) to +3 (changed for the best; Bakas et al., 2006). The responses were recoded as 1–7 to allow for a positive number for analysis based on Bakas et al. (2006). A total score was obtained by adding all of the item scores, with a higher score indicating more positive caregiver outcomes (Bakas et al., 2006). Psychometric testing of the BCOS was conducted using a sample of caregivers of stroke survivors and reported a test-retest reliability of .66 and internal reliability coefficient of .90 (Bakas et al., 2006).

### Recruitment and Retention

Recruitment occurred through two national organizations, the Family Caregiver Alliance (FCA) and YoungStroke; local stroke support groups; targeted Facebook advertisements; and snowball sampling allowing participants to make others aware of the survey. Retention strategies included the option to stop the survey and complete it at another time as well as payment of a \$50 Amazon eGift card for completion of the entire survey.

### Data Collection

Participants accessed the survey through a Research Electronic Data Capture (REDCap) survey link (Harris et al., 2019). The link was made available online through the FCA online listing and newsletters as well as the Facebook advertisements. The survey was also e-mailed directly to YoungStroke’s listserv as well as local stroke support group leaders. Duplicate survey completion was blocked using a CheatBlocker add-on within REDCap (Harris et al., 2019).

## Data Analysis

Data were analyzed using the IBM Statistical Program for Social Sciences (SPSS) v28 software package. Descriptive analysis was conducted on sociodemographic characteristics and caregiver's unmet needs and concerns. Continuous variables were analyzed using mean and standard deviation. Categorical variables and individual items of the CNCC were analyzed using frequencies and percentages. Each of the five domains and the total score for the CNCC were analyzed using the mean, standard deviation, and range. Bivariate Pearson correlation was used to determine the direction and strength of the linear relationship between the individual domains and the total score of caregiver needs and concerns as well as the total scores for stroke survivor functional independence, caregiver strain, self-efficacy, perceived social support, and QoL.

Categorical sociodemographic variables were recoded for inclusion in the regression model because of the small number of respondents in some categories. Race was dichotomized into Black/African American and White. Marital status categories were collapsed into married or living with a partner versus not married (single, separated, divorced, or widowed). The relationship with the stroke survivor was recoded into three binary variables—spouse, parent, and child—with the reference category including brother/sister, other relatives, and friends. Education was dichotomized as college education/no college education. Responsibilities and income were dichotomized as working/not working and less than \$40,000 or \$40,000 or more, respectively. Home was recoded into own/does not own, and transportation was dichotomized as personal private vehicle/other vehicles. Duration of care was recoded as less than 1 year and 1 year or greater.

Linear regression analysis was performed using caregiver QoL as the dependent variable and stroke survivor functional independence, caregiver needs and concerns, caregiver strain, caregiver self-efficacy, and caregiver perceived social support as the independent variables. All assumptions for linear regression were met. Simple linear regression was used to analyze the relationships between the dependent variable and each of the independent variables as well as the continuous sociodemographic variable (age) and transformed sociodemographic variables. Standard and forward multiple linear regression analyses were performed first using QoL as the dependent variable with the combined independent variables. In standard multiple linear regression, all variables were entered into the model simultaneously. In forward multiple regression analysis, the starting point is an empty model, and the independent variables are simultaneously analyzed and then added to the model one at a time until there are no more statistically

significant variables to add. Additional standard and forward multiple linear regression analyses were performed using QoL as the dependent variable, combined independent variables, and the continuous as well as the recoded categorical sociodemographic variables.

## Results

### *Sociodemographic Characteristics*

The participants' average age was 38.7 ( $\pm 12.9$ ) years. Over half of the participants were female, White, married, either the parent or the spouse of the stroke survivor, were working at least part-time, and had been providing care for the stroke survivor for over a year (see Table 1).

### *Unmet Needs and Concerns*

Participants endorsed an average of 13 needs or concerns. Over 50% of participant-reported needs or concerns related to dealing with the stroke survivor's emotions and self-image as well as dealing with their own emotions while providing care. The three needs and concerns expressed most often were (1) keeping the stroke survivor socially active (60%), (2) dealing with other things in the caregiver's life (56%), and (3) dealing with their own emotions while providing care (53%; see Table 2).

### *Correlations*

Stroke survivor functional independence was negatively correlated with caregiver needs indicating that when the stroke survivor had higher functional independence, the caregiver reported fewer needs and concerns. There was a moderate negative correlation with information and total needs and a strong negative correlation with physical and instrumental needs. Caregiver self-efficacy was also negatively correlated with caregiver needs and concerns, meaning that when self-efficacy was higher, needs and concerns were lower. The correlations were moderate with emotion and response needs and weak with total needs and concerns. There were positive correlations between caregiver strain and all domains of caregiver needs, meaning that when strain was higher, needs and concerns were also higher. The correlations were moderate with information and physical needs, whereas correlations with emotion, instrumental, response, and total needs were strong. Caregiver QoL showed a weak positive correlation with caregiver information, physical, and instrumental needs and concerns, which would indicate that as QoL was higher, needs and concerns were also higher. The statistically significant correlations are reported in Table 3.

**Table 1** Sociodemographic Characteristics of Participants (N = 103)

Sample Characteristics	Mean	SD
Age (years)	38.7	12.9
Gender	<b>n</b>	<b>%</b>
Male	40	38.8
Female	63	61.2
Race		
Asian	3	2.9
Black or African American	25	24.3
Other	2	1.9
Prefer not to say	1	1.0
White	72	69.9
Ethnicity		
Hispanic	11	10.7
Non-Hispanic	92	89.3
Marital status		
Divorced	2	1.9
Living with significant other	9	8.7
Married	60	58.3
Separated	2	1.9
Single	30	29.1
Caring for children <sup>a</sup>		
No	53	51.5
Yes	50	48.5
1 child	29	60.4
2 children	19	39.6
Relationship to stroke survivor		
Brother/sister	11	10.7
Child	18	17.5
Friend	4	3.9
Other relative	12	11.7
Parent	33	32
Spouse	25	24.3
Education		
Middle school	2	1.9
High school	13	12.6
College	44	42.7
Graduate school	44	42.7
Degree		
High school diploma/GED	15	14.6
Associates degree	14	13.6
Bachelor's degree	50	48.5
Master's degree	20	19.4
Doctorate	2	1.9
Responsibilities		
Looking for work	4	3.9
On disability	1	1.0
Other	3	2.9
Prefer not to say	1	1.0
Retired	2	1.9
Student	4	3.9
Unemployed or laid off	12	11.7
Working full-time	48	46.6
Working part-time	28	27.2
Income		
Less than \$10,000	6	5.8
\$10,000–\$19,999	6	5.8
\$20,000–\$39,999	15	14.6
\$40,000–\$59,999	17	16.5

(continues)

**Table 1** Sociodemographic Characteristics of Participants (N = 103), Continued

Sample Characteristics	Mean	SD
\$60,000–\$79,999	14	13.6
\$80,000–\$99,999	18	17.5
\$100,000 or more	23	22.3
Prefer not to say	4	3.9
Insurance		
No	16	15.5
Yes	84	81.6
Through employer or union	39	37.9
Purchased directly	10	9.7
Medicaid/medical assistance	22	21.4
Medicare	5	4.9
TRICARE/military	3	2.9
Other	3	2.9
VA	2	1.9
Home		
Owned/being bought	72	69.9
Rented for money	28	27.2
Partial rent on pay scale	2	1.9
Prefer not to say	1	1.0
Financial reserve		
Less than 1 month	4	3.9
1–2 months	9	8.7
3–6 months	28	27.2
7–12 months	11	10.7
More than 1 year	39	37.9
Unsure	10	9.7
Prefer not to say	2	1.9
Transportation		
Personal private vehicle/drives	62	60.2
Personal private vehicle/driven by others	6	5.8
Family or friend's private vehicle	17	16.5
Hospital based clinic transport	3	2.9
Public transportation	14	13.6
Taxi	1	1.0
Duration of care		
Less than 6 months	7	6.8
6–11 months	23	22.3
1–2 years	34	33.0
3–5 years	29	28.2
More than 5 years	10	9.7

Note. N = 103.

<sup>a</sup>Participants did not specify age (n = 4) or number of children (n = 2).

**Simple Linear Regression**

Stroke survivor functional independence, perceived social support, and caregiver self-efficacy were found to be statistically significantly associated with caregiver QoL with stroke survivor functional independence accounting for 7% of the variation in caregiver QoL ( $R^2 = .07$ ,  $F(1, 98) = 7.6$ ,  $B = -0.18$ ,  $p = .007$ ), perceived social support explaining 13% of the variation in QoL ( $R^2 = .13$ ,  $F(1, 98) = 14.5$ ,  $B = 5.00$ ,  $p < .001$ ), and caregiver self-efficacy explaining 38% of the variation in caregiver QoL ( $R^2 = .38$ ,  $F(1, 98) = 61.0$ ,  $B = 0.80$ ,  $p < .001$ ).

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**Table 2** Caregiver Needs and Concerns

Need/Concern	Frequency (%)	Mean	SD	Range
Information needs		3.0	2.5	0–8
Warning signs of stroke	35 (34.0)			
Recommended lifestyle changes after stroke	45 (43.7)			
Risk factors for stroke	39 (37.9)			
Stroke survivor's medications	32 (31.1)			
Stroke survivor's condition or what to expect before going home	21 (20.4)			
How to manage specific problems the stroke survivor may have	43 (41.7)			
Which healthcare professionals to call for advice	32 (31.1)			
Where to find books or written materials, support groups, or organizations that can help	41 (39.8)			
Where I can go for my healthcare needs	20 (19.4)			
Do not need any information at this time	25 (24.3)			
Emotion needs		3.3	2.2	0–6
Dealing with stroke survivor's emotions	53 (51.5)			
Dealing with stroke survivor's feelings about himself or herself	54 (52.4)			
Keeping the stroke survivor socially active	62 (60.2)			
Communicating with the stroke survivor	35 (34.0)			
Dealing with the stroke survivor's changed personality from stroke	42 (40.8)			
Dealing with the stroke survivor's problems with thinking	51 (49.5)			
Dealing with the stroke survivor's difficult behaviors	38 (36.9)			
Do not need any help at this time	15 (14.6)			
Physical needs		1.6	1.5	0–4
Getting the stroke survivor to take medications on time	22 (21.4)			
Getting the stroke survivor to do prescribed exercises	41 (39.8)			
Learning how to help the stroke survivor walk, transfer to a wheelchair, move about, or avoid falls	37 (35.9)			
Getting the stroke survivor to eat	30 (29.1)			
Assisting stroke survivor with bathing, dressing, or going to the bathroom	39 (37.9)			
Do not need any help at this time	31 (30.1)			
Instrumental needs		1.6	1.3	0–3
Learning how to manage checkbooks, bills, forms, or finance related to the stroke survivor's health care	29 (28.2)			
Trying to cover the cost of the stroke survivor's health care	47 (45.6)			
Transporting the stroke survivor places, going out in public with wheelchair, or driving	44 (42.7)			
Finding care for the stroke survivor when I am away	43 (41.7)			
Do not need any help at this time	26 (25.2)			
Response needs		3.3	2.1	0–6
Dealing with my own emotions while providing care	55 (53.4)			
Dealing with new responsibilities that I am not used to	38 (36.9)			
Finding the best way to ask family and friend for help with stroke survivor's care	39 (37.9)			
Dealing with other things in my life	58 (56.3)			
Taking care of my own health	51 (49.5)			
Keeping my energy levels up	51 (49.5)			
Keeping my own social life going	43 (41.7)			
Do not need any help at this time	15 (14.6)			
Total needs		12.7	8.1	0–32

Range represents the number of needs listed in each category selected by participants.

In individual regression models, sociodemographic covariables associated with caregiver QoL included race, gender, relationship to the stroke survivor, transportation, and responsibilities. Race explained 5% of variation in caregiver QoL with Black or African American caregivers having QoL 9.7 points higher than White caregivers ( $R^2 = .05$ ,  $F(1, 92) = 4.8$ ,  $B = 9.7$ ,  $p = .031$ ). Gender explained 9% of variation in QoL with male caregivers QoL 10.4 points higher compared to female caregivers ( $R^2 = .07$ ,  $F(1, 98) = 7.4$ ,  $B = 10.4$ ,  $p = .008$ ). Relationship with the stroke survivor explained 9% of caregiver QoL variation with

QoL of spouses of the stroke survivor 13.1 points lower than other caregiver relationships ( $R^2 = .09$ ,  $F(1, 98) = 9.4$ ,  $B = -13.1$ ,  $p = .003$ ). Responsibilities other than caregiving explained 6% of the variation in caregiver QoL with caregivers working full-time or part-time having 10.63 higher QoL than caregivers who were not working ( $R^2 = .06$ ,  $F(1, 98) = 6.3$ ,  $B = 10.63$ ,  $p = .014$ ).

#### Multiple Linear Regression

Results from the standard multiple regression indicate that the independent variables accounted for 48% of the variation

**Table 3** Correlations

Factor 1	Factor 2	Pearson's <i>r</i>	<i>p</i>
Stroke survivor functional independence	Information needs	-.32	<.001
	Physical needs	-.57	<.001
	Instrumental needs	-.52	<.001
	Total needs	-.36	<.001
Caregiver strain	Information needs	.37	<.001
	Emotion needs	.51	<.001
	Physical needs	.49	<.001
	Instrumental needs	.50	<.001
	Response needs	.55	<.001
Caregiver self-efficacy	Total needs	.55	<.001
	Emotion needs	-.33	<.001
	Response needs	-.37	<.001
Caregiver quality of life	Total needs	-.21	.035
	Information needs	.23	.021
	Physical needs	.29	.003
	Instrumental needs	.24	.017

Statistical significance at the  $p < 0.05$  level.

in caregiver QoL ( $R^2 = .48$ ,  $F(5, 94) = 17.03$ ,  $p < .001$ ). When sociodemographic data were included, the standard multiple regression explained 60% of variation in caregiver QoL ( $R^2 = .60$ ,  $F(17, 72) = 6.46$ ,  $p < .001$ ). In individual models, perceived social support, relationship with the stroke survivor, transportation, and responsibilities outside of the caregiving role were statistically significantly associated with caregiver QoL; however, the relationship was not maintained when the other variables were entered into the combined model. However, with self-efficacy, stroke survivor functional independence, and race, the relationship held when adjusting for all other independent variables. For each one-unit increase in self-efficacy score, QoL increased by 0.67 units. For each unit increase in stroke survivor functional independence, QoL decreased by 0.18 units whereas QoL of Black or African American caregivers was over 9 units higher compared to White participants when adjusted for all other independent variables.

Results from the forward multiple regression indicated an overall model of three covariables (caregiver self-efficacy, stroke survivor functional independence, and caregiver needs and concerns) was associated with caregiver QoL ( $R^2 = .47$ ,  $F(3, 96) = 28.4$ ,  $p < .001$ ). The remaining independent variables were not statistically significant related to QoL. This model accounted for 47% of variance in caregiver QoL. When sociodemographic characteristics were included, an overall model of four covariables (stroke survivor functional independence, caregiver self-efficacy, race, and relationship with the stroke survivor) was associated with caregiver QoL ( $R^2 = .52$ ,  $F(4, 85) = 22.93$ ,  $p < .001$ ). This model accounted for 52% of the variance in caregiver QoL. Table 4 includes the *B* coefficients, coefficient standard

of errors, and *p* values for all statistically significant covariables within each of the forward multiple regression models and for all variables in the standard regression models.

## Discussion

This cross-sectional study suggests that working-age caregivers of stroke survivors have many unmet needs and concerns. The findings suggest correlations between these needs and factors such as stroke survivor functional independence, caregiver strain, caregiver self-efficacy, and caregiver QoL. The study also suggests that caregiver QoL is associated with stroke survivor as well as caregiver characteristics, caregiver self-efficacy, caregiver needs and concerns, and perceived social support.

There were expressed needs in the information, emotions, physical, instrumental, and response domains demonstrating a wide range of unmet needs and concerns, which is consistent with other studies of caregivers of stroke survivors of all ages (Denham et al., 2022; Kokorelias et al., 2020). The domains where the highest number of needs was identified were in the emotion needs and response needs. Emotion needs included dealing with the stroke survivor's emotions, deficits, and behaviors as well as keeping the stroke survivor socially active. Over 60% of participants expressed a need to keep the stroke survivor active socially and 42% of caregivers were concerned about staying socially active themselves. Studies including a broad age range of informal caregivers of stroke survivors focused on the loss of social activity of the caregiver but did not include the unmet need of social activity for the stroke survivor (Denham et al., 2022; Kokorelias et al., 2020). This could

**Table 4** Linear Regression With Caregiver Quality of Life as Dependent Variable

Independent Variable	<i>B</i>	Coefficient <i>SE</i>	<i>p</i>
Simple linear regression			
Stroke survivor functional independence	−0.18	0.07	.007
Caregiver self-efficacy	0.80	0.10	<.001
Perceived social support	5.00	1.31	<.001
Race	9.70	4.42	.031
Gender	10.43	3.82	.008
Relationship with the stroke survivor (spouse)	−13.09	4.27	.003
Transportations	−8.80	3.96	.029
Responsibilities other than caregiving	10.63	4.22	.014
Standard multiple linear regression			
Stroke survivor functional independence	−0.14	0.06	.019
Caregiver needs and concerns	0.51	−0.01	.095
Caregiver self-efficacy	0.82	−0.01	<.001
Caregiver strain	−0.27	0.02	.402
Perceived social support	−0.37	0.29	.876
Standard multiple linear regression with sociodemographic characteristics			
Stroke survivor functional independence	−0.14	0.07	.049
Caregiver needs and concerns	0.03	0.25	.919
Caregiver self-efficacy	0.67	0.16	<.001
Caregiver strain	−0.12	0.37	.755
Perceived social support	−0.73	1.48	.625
Marital status (married or living with partner)	−0.05	3.77	.990
Race (Black/African American)	9.52	3.59	.010
Relationship with stroke survivor (child)	−9.83	5.18	.062
Relationship with stroke survivor (spouse)	−8.03	5.01	.114
Relationship with stroke survivor (parent)	−4.16	4.16	.320
Income (\$40,000 or more)	7.02	4.34	.110
Transportation (personal private vehicle)	0.67	3.73	.858
Home (own/purchasing)	−7.36	3.94	.066
Responsibilities other than caregiver (working)	3.19	3.66	.387
Age	−0.10	0.15	.487
Gender (male)	−7.16	3.46	.042
Ethnicity	−3.83	5.41	.481
Forward multiple linear regression			
Caregiver self-efficacy	0.83	0.10	<.001
Stroke survivor functional independence	−0.13	0.05	.020
Caregiver needs and concerns	0.42	0.20	.036
Forward multiple linear regression with sociodemographic characteristics			
Caregiver self-efficacy	0.80	0.09	<.001
Stroke survivor functional independence	−0.16	0.05	.003
Race	10.28	3.20	.002
Relationship with stroke survivor (child)	−9.14	3.99	.024

Statistical significance at the  $p < 0.05$  level.

be related to the caregivers in this study having a younger mean age than other studies or to the social isolation experienced during the COVID-19 pandemic. Further research of interventions with social activity components could explore the possibility of providing social activity for both the caregiver and stroke survivor. Peer support interventions have shown promise in meeting these social activity needs in both caregivers and stroke survivors (Pucciarelli et al., 2021; Rose, Newman, Lutz, et al., 2022). Response needs included dealing with personal emotions and changes caused by the caregiver's new role as well as their own personal health, social activities, and need for help from family

and friends. These needs are consistent with other studies related to caregivers of all ages (Denham et al., 2022; Kokorelias et al., 2020). There were also several needs related to information regarding stroke, medications, health-care resources, and projected recovery. This need for information is present across all ages of caregivers but may be especially felt by working-age caregivers as their education levels are higher than the generation before them.

The information, emotions, and response domains were close to double in expressed needs per person compared to physical and instrumental needs. This could be due to the range of time the survivor has been receiving care. Caregivers



who have been in their role for a longer period may be more comfortable with the day-to-day skills needed for caring for the stroke survivor and thus may not have as many needs in these areas (Burns et al., 2022). Further research guided by the Timing It Right model, a conceptual model highlighting the changing needs and experiences of caregivers of stroke survivors across the care continuum, could explore the possible change in types of needs over the trajectory of caregiving for stroke survivors (Cameron et al., 2013). These needs also provide an opportunity for further research into the role that rehabilitation nurses can play in meeting these needs of working-age caregivers of stroke survivors.

The number of needs and concerns was statistically significantly correlated with stroke survivor functional independence, caregiver strain, caregiver self-efficacy, and caregiver QoL. There were moderate to strong negative correlations between the total number of needs as well as information, physical, and instrumental needs and stroke survivor function independence. This is consistent with the findings of Denham et al. (2022) where a decrease in stroke survivor functional independence resulted in an increase in caregiver needs. Needs and concerns also had a weak to moderate negative correlation with caregiver self-efficacy. It should be noted that the correlations were specific to emotion needs and response needs as well as total needs. This suggests that higher caregiver self-efficacy is associated with lower levels of needs in the two domains where the greatest needs were expressed. A moderate to strong positive correlation was seen between all five domains and the total needs and concerns and caregiver strain. An increased number of needs correlated with increased caregiver strain. Caregiver QoL was positively correlated with information, physical, and instrumental need domains. However, each of the correlations with caregiver QoL was weak and should be interpreted with caution.

Linear regression analysis revealed several statistically significant predictors of caregiver QoL including perceived social support. This relationship was noted in a scoping review of peer support interventions for caregivers of individuals with cognitive impairment including stroke (Rose, Newman, Lutz, et al., 2022). Kokorelias et al. (2020) noted that connecting informal caregivers of stroke survivors with peers would allow them to discuss and better understand the positive and negative aspects of caregiving. Five caregiver sociodemographic characteristics were also associated with caregiver QoL, which is consistent with studies looking at the specific needs of working-age caregivers as well as male and Black or African American caregivers (Burns et al., 2022; Longacre et al., 2017; Pierce et al., 2019). These relationships identified in the data are also consistent with the model of QoL for informal

caregivers of stroke survivors (Rose, Newman, Lutz, et al., 2022).

### Implications to Nursing Practice and Future Research

The results of this study suggest several avenues for collaboration between nurses, researchers, and working-age caregivers of stroke survivors to address priorities identified by the Association of Rehabilitation Nurses and the American Heart Association (ARN Research Committee, 2019; Green et al., 2021). Future collaborative studies with a strong theoretical framework should be conducted to explore how unmet needs can be met and how they are related to caregiver QoL. Caregiver needs and concerns should also be explored through the lens of sociodemographic factors such as duration of care, gender, and race to further inform the support of a diverse population of informal caregivers. Future studies could also explore the key role of rehabilitation nurses in meeting the needs and concerns of working-age caregivers of stroke survivors, increasing the effectiveness of the rehabilitation and recovery process, transitioning the role of caregiver from the nurse to the family member or friend, and ensuring the best achievable QoL for stroke survivors and their caregivers.

### Limitations

This study has some limitations. The cross-sectional design limits generalizability because it does not measure needs and how they change over the course of the care continuum (Cameron et al., 2013). This design also does not reflect historical or time-sensitive events (both positive and negative) that may have had an effect on survey responses reflecting situational needs and concerns of the caregivers. Lastly, the use of an online survey gives a potential for bias because it does not allow for the inclusion of caregivers who do not have Internet access.

### Conclusion

This study adds to the current literature by exploring unmet needs and concerns of working-age caregivers of stroke survivors and how these correlate with stroke survivor functional independence, perceived social support and caregiver strain, caregiver self-efficacy, and caregiver QoL. A greater understanding of these needs can inform intervention designs to meet the unique needs of a diverse population of informal caregivers of stroke survivors.

### Conflict of Interest

The authors have no conflict of interest to report.

## Key Practice Points:

- Provides information that rehabilitation nurses can use to collaborate with informal caregivers and researchers to inform interventions on postdischarge education related to information, physical, instrumental, emotion, and response needs to promote QoL.
- Aids rehabilitation nurses in addressing the emotions and responses of a diverse population of caregivers of stroke survivors to alterations in functional independence as they transition into their new role as a caregiver.
- Contributes to the knowledge of rehabilitation nurses related to working-age caregivers' needs and concerns as they support stroke survivors and can inform practice to optimize the recovery and rehabilitation process.

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