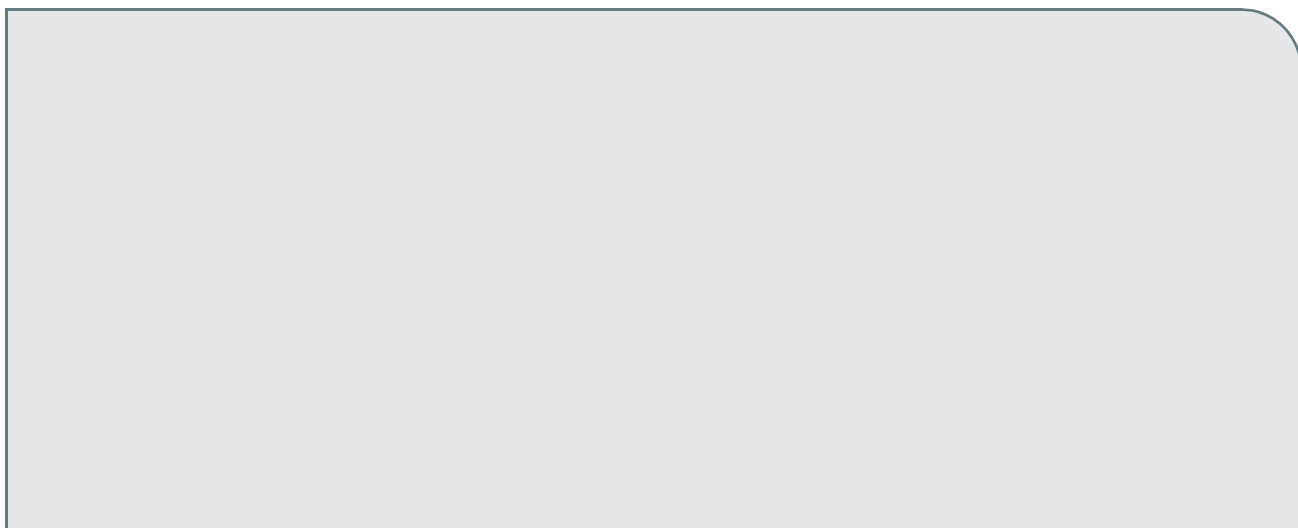


Working-Age Caregivers of Stroke Survivors: Needs, Concerns, and Quality of Life

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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

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 (ADL) that assesses a

Data Analysis

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 ($R^2 = .38$, $F(1, 98) = 61.0$, $B = 0.80$, $p < .001$).

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
Difficult behaviors	38 (36.9)			

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

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

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

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