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Quality of life perceptions of family caregivers of older adults stroke survivors: A longitudinal study

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ABSTRACT

Background: There are few formal outreach and out-patient support services to help family caring for older adults who have had a stroke in developing countries. Family caregivers experience negative changes in their quality of life.
Aim: To assess quality of life perceptions of spouse and non-spouse caregivers of older adult stroke survivors.
Methods: A longitudinal survey study. A convenience sample of forty-eight family caregivers was recruited from the Special Care Stroke Unit at a University Hospital in South Brazil. Quality of life was measured using the World Health Organization's Quality of Life BREF survey upon discharge from the hospital (Time 1) and two months after (Time 2).
Results: Non-spouse caregivers had the lowest Social Relationship scores at Time 1 ($p < .001$) and at Time 2 ($p = .005$), both in terms of personal relationship, the quality of their sex lives and support received from others.
Conclusion: Unfortunately, formal community support programs for family caregivers in Brazil are lacking. Post-stroke caregiving is largely a family affair. Quality of Life assessments among family caregivers of older adult stroke survivors are crucial, particularly after discharge.

1. Background

Stroke is the second leading cause of death in developing countries, particularly in older age (Rodrigues et al., 2013; Vincente-Onabajo, Ali, & Hamzat, 2013). In Brazil, in 2017, 70% of hospitalized stroke patients were older adults (DATASUS, 2018). Stroke can lead to chronic physical and mental impairments that interfere with the most basic daily life activities such as bathing, eating, and dressing (Fens et al., 2014). Older adult patients and their family caregivers must quickly learn how to live with and to manage such impairments at home (Tsai, Yip, Tai, & Lou, 2015).

In Brazil, and in other developing countries, there are very few formal outreach and out-patient support services to help family caring for older adults who have had a stroke. After-stroke care is largely determined as a family responsibility (Fernandes & Soares, 2012). Caregiving is considered women's work. Women are 'expected' to care for sick relatives, partly due to religious beliefs and also to filial piety (Meira, Reis, Gonçalves, Rodrigues, & Philipp, 2017). Primary caregivers of stroke patients are typically spouses and adult children (Costa, Gomes, Viana, Martins, & Costa, 2016; Vieira & Fialho, 2010). The vast majority of family caregivers also do not receive any kind of training or support (Fonseca & Penna, 2008; Rodrigues et al., 2013).

The first year of caregiving is a year of hardship that can affect caregiver health (Haley, Roth, Hovater, & Clay, 2015; Morais et al., 2012). Such hardships include higher perceived stress, anxiety and burden, social isolation, financial and relationship problems, and physical and emotional losses (Green & King, 2009; Lou, Carstensen, Jorgensen, & Nielsen, 2017). Abroad (Baumann, Couffignal, Le Bihan, & Chau, 2012; Persson et al., 2017) and in Brazil (Costa et al., 2016; Costa, Costa, Fernandes, Martins, & Brito, 2015; Lima, Santos, Sawada, & Lima, 2014; Santos & Tavares, 2012), family caregivers experience negative changes in their mental and physical functioning. In addition, declines in stroke survivor functional capacity is associated with declines in caregiver QOL (Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014; Pucciarelli et al., 2017). Spouse caregivers are particularly vulnerable to poor QOL (Caro, Mendes, Costa, Nock, & Cruz, 2017; Persson et al., 2017).

Our study is unique because it focuses on assessing QOL perceptions of both spousal and non-spousal caregivers, and whether such perceptions change over time. We define QOL as the individual's perceptions

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of their position in life, considering the context of the culture, and value system in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL Group, 1995). Our findings provide preliminary knowledge of the QOL priorities of family caregivers. Given the shortage of outreach and outpatient programs to support family caregivers, our findings should be of great interest to Brazilian nurses, and program developers working with families of older adult stroke survivors.

2. Aim

The aim of this Brazilian survey study was to assess and compare quality of life perceptions and priorities among spouse and non-spouse caregivers of older adult stroke survivors. Our research questions were as follows: (Amendola, Oliveira, & Alvarenga, 2011) What are the QOL perceptions of spouse versus non-spouse caregivers of older adult stroke survivors? (Baumann et al., 2012) How do QOL perceptions among spouse versus non-spouse caregivers of older adult stroke survivors change over time? We also hypothesized that spouse caregivers would report lower QOL than would non-spouse caregivers over time.

3. Methods

3.1. Design, setting and participants

This study was a longitudinal survey study. A convenience sample of forty-eight family caregivers was recruited from the Special Care Stroke Unit (SCU-Stroke) at a University Hospital in South Brazil.

Participants were recruited from SCU-Stroke at a University Hospital in Southern Brazil between May 2016 and June 2017. Caregivers' close relationship with care recipients is both a cultural and social norm. Caregivers outside of an older couples' immediate family are considered 'family'. The eligibility criteria were: (Amendola et al., 2011) family caregivers who are 18+ years of age years; (Baumann et al., 2012) taking care of an adult who is 60+ years of age and is a survivor of a stroke; (Bierhals et al., 2017) care recipient has no prior history of stroke; (Bierhals et al., 2017) care recipient had documented evidence of stroke-related functional sequelae on their medical chart. We excluded patients who were: (Amendola et al., 2011) living in a Long-Term Care facility or (Baumann et al., 2012) being followed by Home Care Services after discharge.

Spouse and non-spouse family caregivers were followed approximately one week (Time 1) and two months (Time 2) after their loved one was discharged from a University Hospital SSCU.

3.2. Measurements

Caregivers' were asked about their biological sex, age, education, family income and perceived health. Caregivers were also asked whether they had previous caregiving experience with chronically ill older people, how many days and hours per day they were now providing care, and whether they lived with the older adult stroke survivor. Care recipient functional capacity was already documented on medical records at the SCU. This capacity was captured using the Functional Independence Measure (FIM) (Riberto, Miyazaki, Jorge Filho, Sakamoto, & Battistella, 2001), which measures six dimensions: self-care, sphincter control, transfer, locomotion, communication and social cognition. The lower the score, the lower the functional capacity and the more dependent stroke survivors are on others for help with performing basic activities of daily life.

In Brazil, caregiving typically involves emotional, instrumental and financial supports (Guedes, Lima, Caldas, & Veras, 2017). Emotional support refers to the provision of love and affection. Instrumental support pertains to providing material needs, bathing, dressing, toileting and transferring the stroke survivor, and household chores. Caregivers were asked about whether they received emotional, instrumental and financial from other people.

Family caregiver QOL was measured using the WHOQOL-BREF (WHO, 1996). Two items in this generic QOL instrument pertain to perceived overall QOL and health satisfaction. The other 24 items are housed across Physical Health, Psychological, Social Relationships, and Environment domains. All items are measured on a 5-point Likert scale. The higher the score, the more positive the perception of QOL and health satisfaction over the past 4 weeks.

The WHOQOL-BREF is a reliable and valid instrument for use among Brazilian adults of all ages (Fleck et al., 2000). In this study, Cronbach's Alpha Coefficients for the Physical Health, Psychological, Social Relationships, and Environment domains at Time 1 were 0.83, 0.66, 0.50, 0.71, respectively. Time 2 respective coefficients were 0.77, 0.59, 0.75, and 0.65, respectively. The WHOQOL-BREF has been used in other all-age post-stroke family caregiver studies in Brazil (Caro et al., 2017; Lima et al., 2014) and abroad (Baumann et al., 2012; Jeong, Myong, & Koo, 2015). Family caregivers completed the WHOQOL-BREF at Time 1 and Time 2. Data were collected by a trained undergraduate research assistant in the caregiver's home.

3.3. Data analyses

We used SPSS Version 24.0 to generate frequencies and descriptive statistics for family caregiver characteristics, and their caregiving experiences and QOL. Independent student *t*-tests were used to compare spouse versus non-spouse caregiver age, income, education, days and hours caring for the stroke survivor, health problems, perceived health, the functional capacity of the stroke survivor, and QOL. Chi-square or Fisher's Exact Test was used for between-group comparisons of biological sex, living with stroke survivor, previous experience in caring, and support type.

We engaged in a multivariate analysis of variance (MANOVA) to compare QOL scores between our family caregiver groups. QOL domains that were found to statistically significantly differ between spousal and non-spousal family caregiver groups were further subjected to an item-specific analysis to better understand why such differences were observed. In these item-specific analyses, we controlled for remarkably different aspects of functional capacity among of stroke survivors, along with caregiver characteristics and experiences.

3.4. Ethical consideration

Our study was approved by the Ethical Research Committee of Hospital de Clínicas de Porto Alegre (#160181 – CAEE # 54494616.5.0000.5327). All family caregivers provided informed consent before completing any study questionnaires.

4. Results

Between May 2016 and June 2017, 471 patients were admitted at to the Stroke SCU. Among these, 245 were older adult stroke survivors and 92 of these older adults met our eligibility criteria. Non-participants included 13 family caregivers who declined an invitation to participate, 23 stroke survivors who were living at Long Term Care facility or enrolled in Home Care Programs. Eight older adult stroke survivors passed away during admission. Among the 48 recruited family caregivers, 20 were spouses and 28 were largely adult children. All 48 caregivers completed our Time 1 and Time 2 study questionnaires.

Family caregiver characteristics, health problems, perceived health, caregiver experiences, and stroke survivor functional capacity are shown in Table 1 and Table 2.

4.1. Independent t-tests

Spouse family caregivers tended to be older ($p < .001$), less educated ($p = .002$), and had previous caregiving experience ($p < .001$)

Table 1
Spouse (n = 20) and non-spouse (n = 28) family caregiver characteristics.

Variables	Time[a]	Spouse n(%)	Non-spouse n(%)	*p*
Sex				
Female	Time 1	17(85)	25(89.3)	0.683
Male	Time 1	3(15)	3(10.7)	
Living stroke survivor				
Yes	Time 1	20(100)	23(82.1)	0.066
Prior experience				
Yes	Time 1	19(95)	12(42.9)	< 0.001***
Help with caregiving				
Yes	Time 1	16(80)	26(92.9)	0.218
	Time 2	19(95)	22(91.7)	1.000
Caregiving help				
Instrumental	Time 1	15(75)	24(85.7)	0.460
	Time 2	19(95)	22(91.7)	1.000
Emotional	Time 1	13(65)	20(71.4)	0.636
	Time 2	16(80)	13(54.2)	0.072
Financial	Time 1	4(20)	16(57.1)	0.010**
	Time 2	5(25)	15(65.2)	0.013*
Caregiving orientation				
Yes	Time 1	12(60)	21(75)	0.214
Health problems				
Yes	Time 1	16(80)	20(71.4)	0.499

[a] Time 1: one week after SCU-Stroke discharge. Time 2: two months after SCU-Stroke discharge.
* p < .05.
** p < .01.
*** p < .001.

(Table 2). Non-spouse caregivers reported receiving more financial support at Time 1 (p = .010) and at Time 2 (p = .013). Stroke survivors of non-spouse had the lowest scores of functional capacity at Time 1 (p = .013).

4.2. Domain-specific MANOVA

Adjusted mean QOL scores for spouse and non-spouse family caregivers are presented in Table 3. In our MANOVA, we controlled for remarkably different caregiver characteristics and stroke survivor functional capacity. Spouses had higher Social Relationships QOL scores at Time 1 (p < .001) and at Time 2 (p = .005). To better understand these differences, we examined item-specific scores among spouse versus non-spouse family caregiver in the Social Relationships QOL domain.

4.3. Item-specific MANOVA

At Time 1, we observed a number of statistically significant between-group item score differences. Spouse family caregivers had higher scores for item 20 (personal relationships; p = .028), item 21 (sex life; p = .016), and item 22 (support from friends; p = .011) from the Social Relationships domain (Table 4). At Time 2, item 21 (p = .030) and item 22 (p = .006) scores remarkably differed.

5. Discussion

We assessed QOL perceptions at two points in time among 20 spouse and 28 non-spouse family caregivers. Both caregiver groups were looking after older adult stroke survivors at home. Non-spouse family caregivers had the lowest QOL perceptions at Time 1 and Time 2 in the Social Relationships domain. At the item level, non-spouse family caregivers had the lowest scores with respect to the satisfaction of personal relationships, their sex lives, and support from friends. These findings corroborate those of other Brazilian researchers. Amendola et al. (2011) found that adult child caregivers with ample support from friends or family members reported significantly higher Social Relationship QOL scores than those lacking such support. In two other studies, family caregivers of older adult stroke survivors reported that around-the-clock caregiving severely restricted their social lives (Bierhals et al., 2017; Morais et al., 2012). Chinese caregivers of older adult stroke patients identified support from friends or family as one of their most pressing needs after discharge (Tsai et al., 2015).

In Brazil, around-the-clock caregiving is a culturally revered undertaking. Before discharge from a SCU-Stroke, we recommend that friends and family of non-spouse primary caregivers be educated about how to work together to provide these caregivers with some form of respite. Such conversations should be started prior to discharge to provide anticipatory guidance. Non-spouse caregivers had significantly higher education levels than spouse caregivers; however, they were also far less likely than spouses to have prior caregiving experience. Education is not a proxy for experience. Non-spouse family caregivers may not be able to anticipate which QOL support priorities will be most pressing. Presumably, the good majority of non-spouse caregivers' time is spent providing care to the stroke survivor, as opposed to tending to their own needs such as tending to their social lives outside the home. Ideally, SCU-Stroke policies prompt nurses to identify whom non-spouse caregivers typically turn to for day-to-day support. In other words, who is in non-spouse family caregivers' community support network? In the SCU-Stroke where our caregivers were recruited, no such policies were in place.

Table 2
Spouse (n = 20) and non-spouse (n = 28) family caregiver characteristics and stroke survivor functional capacity.

Variables	Time[a]	Spouse mean(SD)	Non-spouse mean(SD)	Mean difference (95% CI)	*p*
Caregivers					
Age	Time 1	61.30(10.08)	47.86(11.80)	13.44(6.88 to 20.00)	< 0.001***
Monthly family income[b]	Time 1	2487.30(1256.28)	1.951(818.66)	535.87(−118.80 to 1190.54)	0.105
Education (in years)	Time 1	6.28(4.08)	10(3.86)	−3.76(−6.09 to −1.42)	0.002**
Days caring	Time 1	589.90(1514.34)	478.11(1331.61)	11.79(−719.11 to 942.70)	0.788
Hours caring	Time 1	19.00(6.50)	19.57(6.03)	−0.57(−4.24 to 3.10)	0.756
Perceived health	Time 1	3.30(1.12)	3.32(0.81)	−0.02(−0.58 to 0.54)	0.939
	Time 2	3.35(0.98)	3.43(0.83)	−0.79(−0.61 to 0.45)	0.767
Stroke survivors					
Functional capacity (FIM)	Time 1	67.25(19.98)	52.64(18.80)	−14.60(−25.98 to −3.23)	0.013*
	Time 2	82.90(24.10)	68.82(25.90)	−14.07(−29.92 to 0.76)	0.063

[a] Time 1: one week after SCU-Stroke discharge. Time 2: two months after SCU-Stroke discharge.
[b] Family monthly income based on the National Brazilian minimum wage (R$937.00).
* p < .05.
** p < .01.
*** p < .001.

Table 3
WHOQOL-BREF scores for spouse (n = 20) and non-spouse (n = 28) family caregivers.

Domain	Time[a]	Spouse mean(SD)	Non-spouse mean(SD)	Mean difference (95% CI)[c]	*p*[b]
Physical health	Time 1	58.61(5.38)	64.38(4.25)	−5.77(−22.13 to 10.58)	0.480
	Time 2	65.50(5.15)	58.05(4.06)	7.44(−8.19 to 23.08)	0.342
Psychological	Time 1	63.92(4.29)	66.53(3.38)	−2.60(−15.64 to 10.41)	0.688
	Time 2	67.39(3.83)	61.68(3.02)	5.71(−5.92 to 17.35)	0.327
Social relationships	Time 1	82.25(4.51)	56.12(3.56)	26.12(12.40 to 39.84)	< 0.001[***]
	Time 2	76.14(4.69)	55.43(3.70)	20.71(6.45 to 34.97)	0.005[**]
Environment	Time 1	55.97(4.15)	53.54(3.72)	2.42(−10.19 to 15.04)	0.700[*]
	Time 2	60.97(3.45)	56.59(2.72)	4.33(−6.14 to 14.81)	0.409

[a] Time 1: one week after SCU-Stroke discharge. Time 2: two months after SCU-Stroke discharge.
[b] MANOVA or Multivariate Analysis of Variance.
[c] 95% confidence interval. QOL scores are adjusted for caregiver age, education, living with stroke survivor, financial support, previous experience in caring and functional capacity of the stroke survivor.
[*] p < .05.
[**] p < .01.
[***] p < .001.

Table 4
WHOQOL-BREF item scores for spouse (n = 20) and non-spouse (n = 28) family caregiver.

Domain Item	Time[a]	Spouse mean(SD)	Non-spouse mean(SD)	Mean difference (95% CI)[c]	*p*[b]
Social relationships					
Item 20 (How satisfied are you with your personal relationship?)	Time 1	4.29 (0.23)	3.50 (0.18)	0.78 (0.08 to 1.48)	0.028[*]
	Time 2	4.02 (0.18)	3.55 (0.14)	0.47 (−0.09 to 1.04)	0.103[***]
Item 21 (How satisfied are you with your sex life?)	Time 1	4.00 (0.33)	2.74 (0.26)	1.26 (0.24 to 2.28)	0.016[*]
	Time 2	3.80 (0.27)	2.88 (0.21)	0.91(0.09 to 1.74)	0.030[*]
Item 22 (How satisfied are you with the support you get from friends?)	Time 1	5.57 (0.27)	3.48 (0.21)	1.08 (0.26 to 1.91)	0.011[*]
	Time 2	4.30 (0.25)	3.21 (0.20)	1.09 (0.32 to 1.86)	0.006[**]

[a] Time 1: one week after SCU-Stroke discharge. Time 2: two months after SCU-Stroke discharge.
[b] Multivariate Analysis of Variance.
[c] 95% confidence interval. QOL scores are adjusted for caregiver age, education, living with stroke survivor, financial support, previous experience in caring and stroke survivor functional capacity.
[*] p < .05.
[**] p < .01.
[***] p < .001.

Spouse family caregivers of stroke survivors have tended to perceive few encroachments upon their social QOL (Baumann et al., 2012; Jeong et al., 2015; Lima et al., 2014). All spouse family caregivers in this study lived with stroke survivors and their social QOL scores were far higher. Spouses' social lives likely largely revolve around one another. Perhaps this ‘usual living arrangement’ enabled spouse caregivers to feel less social constrained. Intuitively, living with one's own spouse as opposed to living apart would also be less detrimental to one's sex life. Our inferences would be most aptly explored in a qualitative study of non-spouse and spouse family caregivers' social QOL, both prior to and after assuming a full-time caregiver role.

Brazilian families face a number of challenges in their day-to-day living environments. In studies of adults of varying ages (Fleck et al., 2000) and older adults (Paskulin, Vianna, & Molzahn, 2009), mean WHOQOL-BREF scores were lowest in the Environmental domain. Environment QOL was lowest in this study and was, on average, 10–13 points lower than in the latter two studies. Both caregiver groups lived in vulnerable neighbourhoods fraught with poverty, crime, and a lack of access to community health services and public transportation. These issues are widespread throughout Brazil. There are also no economic support programs in place for family caregivers. Moreover, all participants of this study were Public Health Services recipients. Recipients of such services do not have adequate financial resources for private health insurance, which would create affordances for formal caregiver follow-up support after discharge. In light of Brazil's ailing economy, neither scenario is likely to change.

Cross-sectional studies on family caregivers in Brazil (Lima et al., 2014) and abroad (Chuluunbaatar, Chou, & Pu, 2016; Jeong et al., 2015) indicate that non-spouse caregivers are far more vulnerable to poorer Environmental QOL. We found non-spousal caregivers to be most vulnerable two months into the caregiving experience. At Time 2, far more non-spouse family caregivers received financial support (65.2% versus 25% of spouses). Brazilian caregivers generally lack economic resources for mobility and transfer aids for stroke survivors (Oliveira, Garanhani, & Garanhani, 2011) and there are no government specific policies in place to protect caregivers. Home care nurses should explore whether social support networks of non-spouse caregivers would be willing to pool their financial resources to help them manage financial constraints.

Psychological QOL scores were found to be the lowest compared to all other WHOQOL-BREF domains in a study of family caregivers of stroke survivors in Luxembourg (Baumann et al., 2012). In this study, Time 1 Psychological QOL scores were the second highest QOL scores for spouse caregivers and the highest QOL scores for non-spouse caregivers. Time 1 and Time 2 scores for both groups were also not remarkably different. We were further intrigued that, unlike Social Relationships, Psychological QOL scores increased among spouse caregivers. We suspect that these findings are related to filial piety which, in Brazilian society, is considered a moral duty. Most family caregivers in Brazil are also women and the vast majority of our family caregivers were women. Brazilian women are seen as “natural” caregivers who ought to provide any and all forms of support to family members (Giacomin, Uchoa, & Lima-Costa, 2005). Perhaps the Psychological QOL score patterns in this study are rooted in social expectations for Brazilian women.

Across both caregiver groups, perceived health was, at best, modest at Time 1 and Time 2. We were thus puzzled as to why Physical QOL scores generally increased among spouse caregivers whom, logically, were significantly older. Non-spouse caregivers were caring for stroke survivors whom had significantly lower functional capacity at Time 1. However, survivors' functional capacity similarly increased over time across both caregiver groups. In a recent Italian study, improvements in stroke survivors' physical functioning were statistically significantly associated with increases in the physical QOL of their caregivers (Pucciarelli et al., 2017). It is common knowledge that family caregivers experience physical hardships such as fatigue and lack of sleep (Fens et al., 2015; Menon, Salini, Habeeba, Conjeevaram, & Munisusmitha, 2017; Pierce, Thompson, Govoni, & Steiner, 2012). Perhaps the observed increase in physical QOL scores among spouses is also partly owing to filial piety. Reporting physical hardships to an outsider could be perceived as culturally inappropriate disclosure, particularly when the care recipient is a life partner. We had no published Brazilian studies or from developing countries about physical QOL perceptions among spouse or non-spouse family caregivers of stroke survivors with which to compare our findings.

We did face limitations that prevent us from generalizing beyond the studied sample. We recruited a small sample of caregivers from Southern Brazil fraught with environmental and social problems. The QOL scores reported in this study, particularly within the Environment domain, could have been biased by caregiver education and income, and non-spouse caregiver living arrangements. In our next study, we will recruit a larger number of family caregivers by sampling across multiple SSCUs in different geographic regions.

To further explore the lack of significant differences in Physical QOL and score increases among older spouse caregivers, we will collect physical QOL data 12 months after full-time caregiving commences. Physical constraints may take longer than two months to surface. It is also important to concurrently consider the physical functional evolution of stroke survivors. The Caregiver Burden Scale (Medeiros, Ferraz, Quaresma, & Menezes, 1998) will further help us understand our Physical and Psychological QOL findings. Lessening perceived burden over time would strengthen our filial piety inferences. Interviewing male and female non-spousal and spousal caregivers of stroke survivors about their perceived sense of duty will help us further explore filial piety with greater depth.

6. Conclusion

The aim of this study was to assess and compare QOL perceptions among spouse and non-spouse family caregivers of older adult stroke survivors. Non-spouse caregivers had the lowest Social Relationships QOL scores concerning their personal relationships, support received from others, and the quality of their sex lives.

This study is the first Brazilian study to explore QOL perceptions among spouse and non-spouse family caregivers of older adult stroke survivors, and to do so over time using a highly valid and reliable multidimensional QOL measure. The significant perceptual changes that we had observed between our two groups of family caregivers underscore the importance of assessing QOL after discharge from a SSCU. Our item-specific analyses indicate that SCU and Home Care nurses, and program developers ought to pay particular attention to the social relationships of non-spouse caregivers.

Informal support groups could be offered as part of discharge planning by Registered Nurses working in SCUs and in Primary Health Services to help non-spouse caregivers better anticipate what caregiving entails and potential hardships. Transitional care programmes could also be developed by Registered Nurses that take into account caregiver knowledge, skills, financial resources and anticipated formal supports post-discharge. Registered Nurses could also educate family members about the benefits of pooling their monies and energy to further assist non-spouse caregivers. Transitional care programs would be best integrated into Primary Health Services. Ideally, non-spouse caregivers would have more time to tend to their own social relationships.

Further research on caregiver QOL is essential because family caregiver resources in Brazil are largely absent. It is imperative that health program developers are aware of the social and financial QOL hardships that family caregivers of older adult stroke survivors face. Changes for the better requires empirical evidence of family caregiver issues.

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Declaration of Competing Interests

The authors declare no conflicts of interest.

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