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Stroke Survivor and Family Caregiver Reports of Caregiver Engagement in Stroke Care

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Abstract

Purpose: The aim of the study was to identify areas of caregiver engagement in stroke care as viewed by stroke survivors and family caregivers.

Design: Interviews with stroke survivor/caregiver dyads ($N = 71$) from a population-based study of incident stroke.

Methods: We interviewed stroke survivors and caregivers about caregiver involvement at multiple stages of stroke care. We assessed similarities and differences between stroke survivor and caregiver reports and analyzed responses to open-ended questions.

Findings: Stroke survivor and caregiver reports of engagement were highly correlated ($r = .89$), although caregivers reported higher involvement. Open-ended comments suggested that, in about 25% of cases, stroke survivors and caregivers agreed that caregiver engagement led to major improvements in stroke survivor care, most commonly during onset of symptoms.

Conclusions: Stroke survivors and caregivers report significant and impactful caregiver engagement throughout the course of stroke.

Clinical Relevance: Clinicians may enhance stroke care by recognizing and facilitating caregiver efforts across all phases of stroke care.

Keywords: Caregivers; continuity of stroke survivor care; epidemiological studies; stroke; survivors.

Beyond providing assistance with direct care, family caregivers of stroke survivors play key roles in promoting positive stroke survivor outcomes throughout the course of stroke. One study of delays in seeking treatment by stroke survivors found that family members made decisions about going to the hospital in 68% of cases, whereas stroke survivors made only 21% of such decisions (Geffner, Soriano, Pérez, Vilar, & Rodríguez, 2012). Caregivers often want to be involved and do often assist in rehabilitation (Creasy, Lutz, Young, Ford, & Martz, 2013; Randström, Asplund, Svedlund, & Paulson, 2013) and provide extensive tangible assistance (e.g., managing insurance issues, direct care) and emotional support (Cameron, Naglie, Silver, & Gignac, 2013). Caregivers may also reduce the need for emergency department visits after stroke (Roth et al., 2016) while advocating for stroke survivors to receive additional rehabilitative care (Levine et al., 2006).

Previous studies have generally focused on caregiver engagement at specific times in the course of stroke, such as acute care or rehabilitation, or have focused on direct care provision. Much of this research has utilized clinical or convenience samples and has not examined the potentially differing perspectives of the stroke survivor/caregiver dyad. The purpose of this study was to identify major areas of caregiver engagement, throughout the course of stroke, as viewed by the stroke survivor and caregiver. We asked both about caregiver engagement at specific points in the time course of stroke including onset of stroke, hospital care, rehabilitative care, and in-home care. We were particularly interested in whether stroke survivors and caregivers had similar perspectives on how engaged caregivers were and the value of such efforts.

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Cite this article as:
Haley, W. E., Marino, V. R., Sheehan, O. C., Rhodes, J. D., Kissela, B., & Roth, D. L. (2019). Stroke survivor and family caregiver reports of caregiver engagement in stroke care. *Rehabilitation Nursing, 44*(6), 302–310. doi: 10.1097/rnj.0000000000000100

We examined these issues in a population-based sample of stroke survivors and their family caregivers obtained from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study. REGARDS is a prospective epidemiological investigation of stroke incidence and mortality that enrolled 30,239 African American and White male and female participants aged 45 and older from 2003 to 2007 (Howard et al., 2005, 2007). Every 6 months, follow-up telephone interviews are conducted that include queries about hospitalizations, outpatient visits, and symptoms that might indicate possible stroke events. Neurologist adjudicators then examine medical records to confirm stroke events. Stroke survivors identified by the REGARDS project are then recruited, along with a primary family caregiver, to participate in the ancillary Caring for Adults Recovering from the Effects of Stroke (CARES) project (Clay et al., 2013; Grant et al., 2013; Haley et al., 2009; Haley, Roth, Hovater, & Clay, 2015; Haley, Roth, Kissela, Perkins, & Howard, 2011; Roth et al., 2011). In the current project, we assessed stroke survivor and caregiver reports of caregiver engagement, both generally and at specific times across stroke care, and asked open-ended questions to gain concrete examples of situations where stroke survivors and caregivers thought that caregiver engagement altered stroke outcomes. Our analyses focused on the following questions: (1) How commonly do stroke survivors and caregivers say that the caregiver was involved at specific points in stroke care, such as onset of stroke, travel to a hospital, hospital care, and in-home care? (2) Do stroke survivors and caregivers agree on the extent of caregiver engagement in stroke care? (3) What do stroke survivors and caregivers describe as the most common and important ways that caregivers are involved in stroke care?

Materials and Methods

Participants

Participants were 71 stroke survivor/caregiver dyads recruited through REGARDS and CARES. Inclusion criteria for the stroke survivor included living in the community 9 months after the stroke event and having a family member or close friend who had served as an informal caregiver and who was willing to participate. Stroke survivors who resided in nursing homes 9 months after the stroke event were not included in the present analyses.

Each participant received a $20 incentive per interview for participating in this project. The Institutional Review Board of the University of Alabama at Birmingham reviewed and approved all procedures.

Procedures

Data were collected from three sources. A CARES interview was conducted by telephone for the stroke survivor and caregiver approximately 9 months after the stroke event. Trained research interviewers explained the study, screened for eligibility, and obtained verbal informed consent before obtaining project data. Second, at least two trained adjudicators examined medical records for suspected stroke events to determine the date of the stroke, type (ischemic vs. hemorrhagic), cerebral location affected (left hemisphere, right hemisphere, brainstem), length of acute hospital stay, and the discharge status of that hospitalization (e.g., to home, a rehabilitation facility, or nursing home). The third source of data was an in-home evaluation of the stroke survivor conducted approximately 1 year after the stroke event by trained examiners employed by Examination Management Services Incorporated.

Demographic and Descriptive Variables

Age and education in years, gender, and race (African American vs. White) were based on self-report. Data on type and location of stroke, as well as on hospitalization and length of hospital stay, were also recorded for the stroke survivor.

Stroke Caregiver Engagement Scale

We examined previous studies to identify ways that researchers have studied the role of caregivers throughout the course of stroke, including research by Asplund and colleagues (2009), who studied stroke survivor and caregiver satisfaction with stroke care. A pool of possible items was generated and reviewed by the CARES research team, including a neurologist and nurse with experience with stroke care. Our final pool of 10 items was administered during the telephone interviews, and stroke survivors and caregivers independently rated each caregiver engagement item on a 0 (*not*) to 3 (*very*) scale. These ratings were summed to form a total score. Caregivers were asked to consider the entire period of stroke care and, for each item, respond to the question: "How active were you in helping your family member with the following needs?" Stroke survivors were asked to report on "how involved your family" was for those same 10 items.

Other Reports of Caregiver Engagement

In addition to questions on the Stroke Caregiver Engagement Scale (SCES), which included all phases of stroke, we asked stroke survivors and caregivers about caregiver involvement in specific aspects of care. Items included whether family members were present during onset of symptoms; if family members were contacted before seeking treatment; means of transportation to the hospital; length of time (minutes) from onset of symptoms to reaching the hospital; whether family members or friends voiced concerns about stroke survivor care during hospitalization; whether family members or friends voiced concerns about care during or after discharge; and whether family requested additional rehabilitation or training. Stroke survivors and caregivers responded using categories, except for time to hospital, which were assessed in minutes.

Open-Ended Questions

We also asked stroke survivors and caregivers open-ended questions concerning caregiver engagement. Stroke survivors were asked, “Can you give us an example of a time when you think that the efforts of your family members made a difference in allowing you to get more medical or rehabilitative care? Did anything happen since your stroke that made your family become much more, or much less, involved in being an advocate for you to get more medical or rehabilitative care?” Caregivers were asked nearly identical questions asking about their own or other family members’ engagement. Interviewers provided detailed summaries of the responses to these open-ended questions. Whereas in most cases the identified primary caregiver was the most engaged, in some cases caregivers and stroke survivors reported on efforts by other family members (e.g., a daughter’s involvement although the wife was the primary caregiver).

Responses were categorized as indicating little or no engagement, minor engagement, or major engagement by the caregiver. Minor caregiver engagement was operationalized as actions by the caregiver that, although valuable, did not have a significant impact on the quality of care the stroke survivor received or on poststroke outcomes. Major caregiver engagement was operationalized as caregiver actions that respondents believed had a significant impact on the quality of care received by the stroke survivor. We also rated whether these indicators of engagement occurred at the time of onset of stroke symptoms, during hospitalization, or after discharge. Two of the authors rated a sample of these responses independently and concurred on their categories over 90% of the time.

Stroke Impact Scale

This instrument, administered at the 1-year home visit, has 64 items that assess stroke survivor self-assessments of eight domains of functioning: strength, memory, emotion, communication, activities of daily living and instrumental activities of daily living, mobility, hand function, and social participation. The Stroke Impact Scale (SIS) has excellent reliability and validity and is commonly used as a means of assessing stroke outcomes and quality of life (Ali, Fulton, Quinn, Brady, & VISTA Collaboration, 2013; Duncan et al., 1999). Each subscale ranges from 0 to 100, with higher scores indicating better functioning.

Center for Epidemiological Studies-Depression Scale

We used the widely used and validated Center for Epidemiological Studies-Depression Scale (Head et al., 2013; Radloff, 1977) as a measure of stroke survivor and caregiver depressive symptoms. For each of the 20 items, stroke survivors and caregivers rated the frequency of each symptom on a 0 (*rarely*) to 3 (*most of the time*) scale. Higher scores indicate greater depressive symptoms. The Center for Epidemiological Studies-Depression Scale showed internal consistency of .89 in caregivers and .90 in stroke survivors in a recent study (Grant et al., 2013).

Results

Demographic and descriptive information for the 71 dyads is shown in Table 1. The stroke survivors in our sample averaged 67 years of age, were above average in education, and were 46.5% female. Caregivers were somewhat younger, averaging 61 years of age, and also above average in education. As is commonly found in caregiving studies, most of the caregivers were female. The sample is about 2/3 White and 1/3 African American, and in most cases race is the same in these dyads. Although nonfamily caregivers were eligible for the study, all caregivers included in this analysis were family members. They included spouses or other romantic partners (47.9%), children of the stroke survivor (39.4%), and other family members (12.7%).

In terms of the location of the stroke event, 44% were left hemisphere, 44% were right hemisphere, and 12% were brainstem. For type of stroke, 90% were ischemic and 10% were hemorrhagic. Most stroke survivors (92%) were hospitalized for their stroke events, and the average length of those hospitalizations was 6.3 days (SD = 7.1).

Results from the comparisons of stroke survivor and caregiver reports on individual items and overall scores for the SCES are shown in Table 2. Mean differences were compared via t tests between stroke survivors and caregivers, and Spearman r correlation coefficients were computed between stroke survivor and caregiver reports. Reports between stroke survivors and caregivers were highly correlated for each item, with Spearman rs ranging

Table 1 Demographic information and standardized regression estimates for stroke survivors and family caregivers (*N* = 71 dyads)

	Demographic and Descriptive Variables		Standardized Regression Estimates Associated With Stroke Survivor Engagement Score	Standardized Regression Estimates Associated With Caregiver Engagement Score
Stroke survivor	Age (*M* ± *SD*)	67.3 (6.7)	0.221 (0.064)	0.149 (0.126)
	Years of education (*M* ± *SD*)	14.0 (2.7)	−0.210 (0.079)	−0.151 (0.209)
	Gender, % female	46.5	0.188 (0.11)	0.254 (0.032)
	Race, % African American	32.4	−0.023 (0.85)	−0.007 (0.950)
	CES-D baseline (*M* ± *SD*)	6.1 (6.7)	0.379 (0.0012)	0.065 (0.60)
	Length of hospital stay (days)	6.3	0.263 (0.037)	0.266 (0.04)
	SIS Strength	75.3	−0.52 (0.0003)	−0.470 (0.0013)
	SIS Memory	85.6	−0.062 (0.689)	−0.066 (0.668)
	SIS Emotion	81.5	−0.517 (0.0003)	−0.458(<0.001)
	SIS Communication	93.1	−0.246 (0.108)	−0.242 (0.003)
	SIS ADL/IADL	85.1	−0.452 (0.0024)	−0.431 (0.0039)
	SIS Mobility	78.1	−0.439 (0.0029)	−0.404 (0.007)
	SIS Hand function	81.8	−0.460 (0.0017)	−0.474 (0.0011)
	SIS Social participation	81.8	−0.10 (0.51)	−0.124 (0.436)
Caregiver	Age (*M* ± *SD*)	61.1 (14.2)	0.05 (0.67)	−0.069 (0.571)
	Years of education (*M* ± *SD*)	14.7 (2.4)	−0.146 (0.232)	−0.098 (0.423)
	Gender, % female	77.1	0.03 (0.79)	0.068 (0.577)
	Race, % African American	32.9	−0.04 (0.76)	−0.014 (0.907)
	CES-D baseline (*M* ± *SD*)	4.6 (7.3)	0.065 (0.60)	0.093 (0.452)

Note. M = mean; *SD* = standard deviation; CES-D = Center for Epidemiological Studies-Depression Scale; SIS = Stroke Impact Scale; ADL = activity of daily living; IADL = instrumental activity of daily living.

from .61 to .84, but caregivers reported significantly higher engagement on 7 of the 10 items and on total score. Coefficient alpha for the SCES are .94 for stroke survivors and .92 for caregivers. Total scores on the SCES for stroke survivors and caregivers were highly correlated, with $r = .89$.

Other Reports of Caregiver Engagement

Reports from stroke survivors and caregivers were generally highly consistent on these items, so only stroke survivor reports are summarized here. Where discrepancies occurred, caregivers generally reported higher levels of caregiver engagement. Stroke survivors reported that caregivers or other family were present 76% of the time during the onset of stroke, that family members were contacted 71% of the time before seeking treatment, and that family encouraged the stroke survivor to go to the hospital 80% of the time. Stroke survivors reported that family members drove them to the hospital 60% of the time and 40% said they traveled by ambulance. Stroke survivors reported that it took a median of 55 minutes to reach the hospital after the onset of symptoms. Stroke survivors largely reported that caregivers had no engagement in raising concerns during hospitalization (93%), about care after discharge (95%), or in pressing for additional rehabilitation beyond what was provided (84%). Both stroke survivors and caregivers often commented during open-ended questions (with some notable exceptions) that they received excellent care in the hospital and did not have concerns about needing additional services.

We examined the association between SCES and other measures to assess discriminant and convergent validity. We expected that more severe impairments and longer duration of hospitalization would be associated with higher levels of caregiver engagement. We also computed correlations between stroke survivor and caregiver scores on the SCES and demographic factors, and indicators of caregiver well-being, which we did not expect to be significantly correlated with SCES scores. Standardized regression coefficients of the association between SCES scores for stroke survivors and caregivers and variables examined for assessment of convergent and discriminant validity are shown in Table 1. Both stroke survivor and caregiver SCES scores were significantly associated with indicators of greater stroke survivor impairment, including greater length of hospital stay, more stroke survivor depressive symptoms, and poorer stroke survivor functioning on six of the eight subscales on the SIS. We found only one of the 16 regression scores calculated between the stroke survivor and caregiver SCES scores and stroke survivor/caregiver demographic variables were statistically significant. SCES scores were also not significantly associated with caregiver depressive symptoms. These results are also of interest in terms of examining whether

Table 2 Items on the Stroke Caregiver Engagement Scale, ranked by stroke survivor rating of caregiver engagement

Item	Stroke survivor, *n* =71	Caregiver, *n* =71	Difference *p*	Spearman *r*
Providing encouragement	2.10	2.38	.03	.61
Working to keep things positive	1.83	2.09	.05	.68
Arranging transportation to appointments	1.66	1.96	.006	.79
Finding information about stroke and stroke prevention	1.51	1.65	.29	.65
Picking up prescriptions	1.46	1.70	.03	.75
Scheduling appointments	1.30	1.54	.038	.72
Providing motivation to work hard in therapies	1.20	1.15	.71	.74
Working to find meaningful roles after stroke	1.18	1.49	.01	.70
Obtaining additional medical equipment or supplies	1.08	1.15	.37	.84
Dealing with insurance issues	0.99	1.24	.017	.77
Total engagement	14.31	16.37	.0006	.89

demographic factors are associated with stroke survivor and caregiver reports of caregiver engagement. No significant association between stroke survivor or caregiver age, education, race, or gender and either stroke survivor or caregiver reports of stroke survivor engagement were found.

Responses to Open-Ended Questions

Examples of stroke survivor and caregiver responses to open-ended questions are shown in Table 3. Most (65%) dyads showed agreement on the level of impact on care. Among stroke survivors, 48% reported no impact, 27% reported minor impact, and 25% reported major impact of caregiver engagement on stroke care. Among caregivers, 48% reported no impact of caregiver engagement, 15% reported minor impact of caregiver engagement, and 37% reported major impact of caregiver engagement on stroke care. Seventy-two percent of stroke survivors and 58% of caregivers who reported major impact of caregiver engagement said that this impact came at the time of stroke, whereas 28% of stroke survivors and 38% of caregivers said that this impact came at the time of hospitalization. Many caregivers (34%) and stroke survivors (25%) spontaneously reported satisfaction with the quality of medical care received by the stroke survivor.

Discussion

The study's results show that both stroke survivors and caregivers describe caregiver engagement as significantly affecting stroke care. Stroke survivors and caregivers agreed that caregivers often played critical roles at the time of onset of stroke symptoms. A majority reported that caregivers had been either present or were immediately contacted when symptoms occurred, that caregivers played key roles in encouraging stroke survivors to seek care, and, in about 1/3 of cases, that the caregiver drove the stroke survivor to the hospital.

When asked open-ended questions about whether stroke survivor engagement had an impact on stroke care, 54% of stroke survivors and caregivers provided examples. Most examples focused on onset of symptoms. We received some remarkable examples of caregivers intervening aggressively at this time. Caregiver intervention at symptom onset had a major impact on care as it often influenced stroke survivors' decision to get medical treatment in a timely manner. Several caregivers and stroke survivors reported that stroke survivors would not have gone to the hospital at all if not for caregiver intervention.

These findings have important implications for practice including the importance of caregivers' roles in the immediate recognition of stroke symptoms and quick activation of Emergency Medical Systems. The literature is very clear in that the prompt activation of Emergency Medical Systems with emergent treatment intervention improves the odds of good functional outcomes (Jauch et al., 2013). Ongoing education of the public, a large portion of which may eventually become caregivers, regarding the signs and symptoms of stroke and emergent intervention is very important.

Interestingly, there were no significant differences in caregiver or stroke survivor reports of engagement related to demographic variables including age, educational attainment, gender, or race. Race and cultural variables can play an important role in caregiving. Previous research has shown that African American caregivers tend to care for stroke survivors with more severe impairments, but after adjustment for this, show less psychological distress than White caregivers (Clay et al., 2013). The present findings suggest high levels of caregiver engagement regardless of these demographic differences.

There were fewer reports of caregivers having a major impact on care during acute hospitalization. Many stroke survivors and caregivers commented that they

Table 3 Examples of stroke survivor and caregiver reports of caregiver engagement by level and time of impact

Stroke survivor	None		"Had very good care…do not think it would have been different without friends and family."
	Minor	Onset	"When having chest pains before the surgery daughter encouraged [patient] to get it checked out. Daughter goes with her to [appointments] and son helps around the house with rehab care. She says she makes her own decisions but their concern and influence encourages her."
		Hospitalization	"Family was supportive but [patient] feels she received very good care and there was no need for additional advocacy. She is a retired nurse."
		Discharge	"Spouse looks closely after diet and exercise, she encouraged me in my recovery and continues to pursue any avenue that might help prevent future strokes."
	Major	Onset	"[Patient] would not have gone to the hospital without the insistence of her family and could have potentially suffered significantly more severe side effects."
		Hospitalization	"ER doctors were eager to dismiss [patient's] symptoms as stomach problems [because] she was vomiting and sent her home. Daughter was adamant that they continue to pursue the cause of her problems looking for heart and stroke signs. [Patient] is not sure what would have happened to her if her daughter had not been there to intervene."
		Discharge	N/A
Caregiver	None		"Caregiver feels that he had excellent medical care and would have gotten same care with or without family advocacy."
	Minor	Onset	"Caregiver expressed concern over symptoms and encouraged him to seek medical attention but it was ultimately the [patient] who made the decision to go."
		Hospitalization	"Daughter is [doctor] so she helped them understand what the [doctors] were saying."
		Discharge	"Caregiver tries very hard to ensure [patient] makes it to all of his [appointments] and takes care of himself at home as he is instructed by doctors."
	Major	Onset	"[Patient] would not have pursued additional care if [caregiver] was not there to realize potential serious symptoms."
		Hospitalization	"Dorothy fought for additional rehab when they tried to discharge Joseph and he could still not use his legs."
		Discharge	N/A

had received excellent care in the hospital and that there was no need for them to advocate for better care or more rehabilitation services. This high satisfaction may be due to increased efforts to improve stroke care in hospitals (Fonarow et al., 2014; Schwamm et al., 2013) or because of innovative programs such as early supported discharge with home based rehabilitation (Hillier & Inglis-Jassiem, 2010). There were 16 examples (out of 142 total reports by stroke survivors and caregivers) in which caregivers or stroke survivors reported poor care in hospitals, and in these cases caregivers had a high impact on care, serving as strong and effective advocates for additional medical testing, longer inpatient stays, and improved safety precautions, pain management, and personal hygiene and comfort care. Having a caregiver to serve as a strong advocate reportedly prevented stroke survivors from being discharged too quickly or having serious symptoms ignored.

There was strong agreement between stroke survivors and caregivers on SCES items that caregivers played key roles in a number of elements of care. Some of the most strongly endorsed were indicators of providing emotional help, such as providing encouragement and helping keep things positive. Providing stroke survivors with information about poststroke care and prevention was also highly endorsed.

Although stroke survivors and caregivers showed high agreement, caregivers reported higher engagement across 7/10 items and on the total scale. Neither of these reports can be viewed as a gold standard; they represent different perspectives. Previous studies examining the reliability of proxy reports on various stroke survivor domains have found high proxy/stroke survivor agreement concerning the more concrete domains such as activities of daily living assistance, but poor agreement in subjective domains like pain and well-being (Carod-Artal, Coral, Trizotto, & Moreira, 2009). Caregivers may be more aware of some kinds of assistance that they provide but may also be motivated to see themselves as instrumental.

The SCES could be valuable in studying several important questions. Higher levels of caregiver engagement might lead to enhanced stroke survivor recovery or better utilization of poststroke formal care (Roth et al., 2016), especially when stroke survivors have high levels of impairment.

This project had significant strengths, including its use of a population-based sample. But there were important limitations as well. Our sample size for these analyses is relatively small, so we were not able to examine differences between dyads related to factors such as the stroke survivor–caregiver relationship. Although nonfamily caregivers were eligible for the study, similar to many previous studies, all caregivers were family members. It is important to see more research on nonfamily caregivers and how caregiving differs in such circumstances. Although the SCES appears promising, it should be evaluated in other studies. Finally, although we studied both Whites and African Americans, the relevance to other racial/ethnic groups deserves further study as well.

Stroke creates a significant burden on support systems of the stroke survivor. A stroke event is especially challenging with higher degrees of neurologic deficit and disability, and caregivers are an integral part of the recovery process (Winstein et al., 2016). Recently published Guidelines for Adult Stroke Rehabilitation and Recovery espouse the involvement of the caregiver at all aspects of the care spectrum, from the acute stroke onset to the rehabilitation setting (Winstein et al., 2016). These guidelines reinforce the notion that it takes a large, coordinated team working collaboratively with the stroke survivor and caregiver to achieve full recovery potential. Beyond the provision of direct care with daily activities, an additional aim of intervention could be to prepare caregivers for roles as active participants and advocates in stroke care. For example, caregivers may be engaged in physical therapy programs in stroke survivor settings to enhance transfer of skills to home settings. Caregiver education about community resources and ways to advocate for more care could become an area of greater emphasis. A major recent report on family caregiving (National Academies of Sciences, Engineering, and Medicine, 2016) provides detailed examples of policy changes that could enhance the roles of family caregivers, including increasing access by caregivers to stroke survivor records, and inclusion of family caregivers as part of a patient–healthcare professional–caregiver team.

Key Practice Points

- Stroke survivors and caregivers agree caregivers' emotional, tangible, and informational assistance affects stroke outcomes.
- Caregiver engagement most significantly affects stroke care at symptom onset.
- Professionals who work in stroke rehabilitation and care should attend to and work to enhance the important roles that family members can play throughout the course of care following stroke.
- Future research should examine the roles of caregivers in enhancing quality and outcomes of stroke care.

There is already increasing research on efficacy of interventions to improve functioning and well-being in the stroke survivor and caregiver (Bakas et al., 2014). With early diagnosis and treatment of stroke being crucial for increasing survival and reducing disability, it is important that caregivers continue to act as strong and effective advocates starting from the onset of symptoms and continuing through the continuum of stroke care (Koksal, Gazioglu, Boz, Can, & Alioglu, 2014).

Summary and Conclusions

Our results show that both stroke survivors and caregivers report high levels of caregiver engagement throughout the course of stroke, well beyond the widely acknowledged role of providing assistance with activities of daily living and other tasks. Efforts to enhance the role of the family caregiver and to identify ways that caregivers can enhance the effectiveness of stroke outcomes should be major priorities for future research.

Acknowledgments

This research project was supported by a cooperative agreement (U01 NS041588) and by an investigator-initiated grant (R01 NS075047) from the National Institute of Neurological Disorders and Stroke, National Institutes of Health, Department of Health and Human Service.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Neurological Disorders and Stroke or the National Institutes of Health. Representatives of the funding agency have been involved in the review of the manuscript but not directly involved in the collection, management, analysis, or interpretation of the data.

The authors thank the other investigators, the staff, and the participants of the REGARDS study for their valuable contributions. A full list of participating REGARDS investigators and institutions can be found at http://www.regardsstudy.org.

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