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CITATION

Atteih, Samar; Mellon, Lisa; Hall, Patricia; Brewer, Linda; Horgan, Frances; Williams, David; et al. (2015): Implications of stroke for caregiver outcomes: findings from the ASPIRE-S study.. Royal College of Surgeons in Ireland. Journal contribution. https://hdl.handle.net/10779/rcsi.10773665.v1

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Implications of stroke for caregiver outcomes: findings from the ASPIRE-S study

Samar Atteih[1], Lisa Mellon[1]*, Patricia Hall[2], Linda Brewer[2], Frances Horgan[3], David Williams[2], and Anne Hickey[1] on behalf of the ASPIRE-S study group

Background **Informal caregivers are vital to the long-term care and rehabilitation of stroke survivors worldwide. However, caregiving has been associated with negative psychological outcomes such as anxiety and depression, which leads to concerns about caregiver as well as stroke survivor well-being. Furthermore, caregivers may not receive the support and service provision they require from the hospitals and community.**

Aims **This study examines caregiver psychological well-being and satisfaction with service provision in the context of stroke.**

Methods **Caregiver data were collected as part of the ASPIRE-S study, a prospective study of secondary prevention and rehabilitation which assessed stroke patients and their carers at six-months post stroke. Carer assessment included measurement of demographics, satisfaction with care (UK Healthcare Commission National Patient Survey of Stroke Care), psychological distress (Hospital Anxiety and Depression Scale), and vulnerability (Vulnerable Elders Scale). Logistic regression analyses and chi-squared tests were performed using STATA version 12.**

Results **Analyses from 162 carers showed substantial levels of dissatisfaction (37·9%) with community and hospital services, as well as notable levels of anxiety (31·3%) and depressive symptoms (18·8%) among caregivers. Caregiver anxiety was predicted by stroke survivor anxiety (OR = 3·47, 95% CI 1·35–8·93), depression (OR = 5·17, 95% CI 1·83–14·58), and stroke survivor cognitive impairment (OR 2·35, 95% CI 1·00–5·31). Caregiver depression was predicted by stroke survivor anxiety (OR = 4·41, 95% CI 1·53–12·72) and stroke survivor depression (OR = 6·91, 95% CI 2·26–21·17).**

Conclusion **Findings indicate that caregiver and stroke survivor well-being are interdependent. Thus, early interventions, including increased training and support programs that include caregivers, are likely to reduce the risk of negative emotional outcomes.**

Key words: caregivers, informal caregivers, satisfaction with care, secondary prevention, stroke outcomes, well-being

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Received: 2 September 2014; Accepted: 18 February 2015

Conflicts of interest: None declared.

Funding: The ASPIRE-S research was supported by a Health Research Award from the Irish Health Research Board (HRB; grant number 1404/7400).

DOI: 10.1111/ijs.12535

Background

Informal caregivers have for years provided a key means of support for stroke survivors globally. Informal caregivers are defined as those who provide unpaid assistance to others, usually a family member or friend, following onset of chronic illness or disability (1). According to the Irish National Audit of Stroke Care (INASC), there are approximately 30,000 stroke survivors in Ireland, many of whom required the support of informal caregivers to carry out their daily activities (2).The support required can be extensive and demanding as stroke often leads to physical, cognitive, and psychological deficits in survivors (3–6).

Considering the fact that many caregivers will be the primary source of support for stroke survivors, it is important that they receive a variety of services ranging from training programs on effective rehabilitation skills to more personalized services such as support groups and help lines (1,7). Caregivers worldwide show varying levels of satisfaction with service provision, and there is a need for increased knowledge, understanding, and management of these issues by clinicians and community support services (7–9). This holds true for the Irish population of stroke survivor caregivers; in only approximately one-quarter of cases studied in the INASC study were caregiver needs assessed, and furthermore, caregivers were trained formally in only 12% of cases (2).

Previous research has established the increased prevalence of negative emotional outcomes among stroke survivor caregivers (10,11). The prevalence of depressive symptoms among caregivers ranges from 11% to 61% and from 14% to 28% for anxious symptoms (12). Much research has been undertaken on the relationship of this increased prevalence of emotional distress to factors such as caregiver age, gender, stroke severity, stroke survivor depressive symptoms, and the acute phase depression in carers (10,13). However, existing caregiving literature in the context of stroke tends to overlook potential relationships between the increased prevalence of anxiety and depression among caregivers with subjective factors, such as caregiver dissatisfaction with service provision, and focuses instead on the demographic and clinical factors just described. This study provides a broader exploratory analysis to include potential relationships that are not well described in existing literature.

Aims

The Action on Secondary Prevention Interventions and Rehabilitation in Stroke (ASPIRE-S) study is a prospective study which assessed stroke patients and their caregivers at six-months post-stroke. The primary aim was to profile secondary preventive strategies, the delivery of community rehabilitative need, and the ongoing rehabilitative need of stroke survivors. A secondary objective of the ASPIRE-S study was to explore caregiver

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satisfaction with care and to capture the psychological outcomes of stroke on stroke survivor caregivers in order to comprehensively describe the rehabilitative journey for stroke survivors and their caregivers. The aim of the analysis presented in this study was to comprehensively profile stroke survivor caregivers and, in doing so, determine the factors that influence the incidence of anxious and depressive symptoms in this population. We hypothesized that poorer stroke survivor outcomes would be related to poorer caregiver psychological outcomes.

Materials and methods

Study design

Caregiver data were collected as part of a larger prospective study, the ASPIRE-S study (14). ASPIRE-S is a prospective study which recruited consecutively across a 12-month time frame (14). Following case recruitment at the hospital, baseline demographic and clinical details were recorded for all patients and their caregiver. After six-months, a physician researcher, research nurse, and research assistant conducted home interviews and assessed both patients and caregivers. For stroke survivors, clinical efficacy markers such as blood pressure, height, and weight were measured, as well as pharmacological secondary prevention through laboratory analysis. For stroke survivors, questionnaires and direct observation tests were used to measure on-going rehabilitation need, functional status, and psychological function. The detailed stroke survivor assessment is described elsewhere (14). Stroke survivor measures included in this analysis include stroke survivor functional status [measured using the modified Rankin Scale (mRS) (15), stroke severity (measured using the Scandinavian Stroke Severity Scale (16)], presence of anxious or depressed symptoms [measured using Hospital Anxiety and Depression Scale (HADS)-Anxiety and HADS-Depression (17)], cognitive impairment [measured using the Montreal Cognitive Assessment (MoCA) (18)], and vulnerability [measured using the Vulnerable Elders Scale (VES) (19)].

The caregiver questionnaire was the primary source of caregiver data for this study. Caregivers received a postal questionnaire one-week prior to the ASPIRE-S home assessment with the stroke survivor and the caregiver. During the ASPIRE-S home assessment, caregivers were provided with the opportunity to clarify any questions presented in the questionnaire, and ASPIRE-S researchers ensured completeness of questionnaire completion. The questionnaire was divided into four sections as follows:

Demographics: This section included characteristics such as gender, age, and relationship to patient.

Satisfaction with care: The Quality of Care Survey from the UK Healthcare Commission National Patient Survey of Stroke Care was used, and was adapted for use with caregivers (20,21). The scale is a 25-item measure, with responses scored from 0 (strongly agree) to 4 (strongly disagree), for each question. The total score possible was 100, with higher levels indicating greater dissatisfaction. Total levels of satisfaction were scored as follows: 0–24: very satisfied, 25–49: moderately satisfied, 50–74: moderately dissatisfied, and 75–100: very dissatisfied.

The HADS: This is a 14-item questionnaire which asks patients to self-assess their feelings throughout the previous week (17). It is divided into two sub-sections of seven questions each: HADS-A for anxiety and HADS-D for depression, with a score between 0 (no symptoms) and 3 (maximum anxious/depressive symptoms) for each question. The total possible score for each sub-section was 21. In this study, a cutoff score of greater than or equal to 8 for each subsection was taken to indicate anxious or depressive symptoms accordingly. This cutoff point is commonly used in research (22).

Vulnerability: The VES is a 13-item measure of vulnerability, which calculates a total score between 0 and 13 based on age, self-rated health, difficulty carrying out physical activity (such as stooping and heavy housework), and difficulty carrying out simple daily activities (such as shopping and managing money). A score of 13 indicates the highest level of vulnerability, and scores above a cut-off of 3 indicate increased risk of mortality within two-years (19).

Statistical analyses

Descriptive statistics, chi-squared (χ^2) tests, and logistic regression analyses were used to assess the relationship between caregiver indicators of differences on demographic variables. Continuous variables were presented as means [standard deviation (SD)], while categorical and binary variables were presented as frequencies and proportions.

For the analysis of the presence and strength of associations between caregiver satisfaction with care, stroke survivor clinical variables, and measures of caregiver emotional distress, logistic regression was employed. The specified outcomes in logistic regression modeling were presence of symptoms of anxiety and depression as binary variables, derived from applying the HADS cutoffs of >8 to indicate presence or absence of anxious or depressed symptoms. Considerations for modeling sample size were applied to avoid over-fitting of the models and subsequent production of biased estimates of effect size (23,24). Given the small numbers meeting the outcomes of interest, adjusted analyses were not possible, and crude odds ratios (OR), therefore, are reported. Previous literature to date has not provided any consistent relationship between demographic variables and mental health in caregivers, and exploratory regression modeling with reporting of unadjusted regression coefficients has been previously employed with stroke caregiver cohorts (10,11,13).

Ethical approval

Ethical approval was granted from the research ethics committees of each of the three participating hospitals.

Results

The final dataset included a total of 302 stroke survivors recruited across three Dublin hospitals in a 12-month period. Of these, 256 were followed up in the community six-months later. One-hundred and ninety stroke survivors identified a next of kin: 80% were spouses or partners of the stroke survivor, 17% were family

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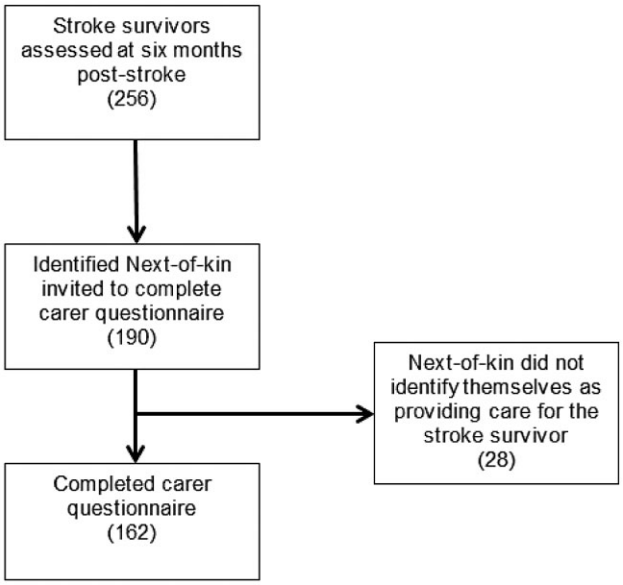


Fig. 1 Flow diagram of participant recruitment.

members, and 3% were friends. Twenty-eight individuals identified as the next of kin did not identify themselves as a caregiver for the stroke survivor and thus declined to complete the carer questionnaire (Fig. 1).

Profile of the stroke survivors

Of the stroke survivors who had primary caregivers included in this study ($n = 162$ stroke survivors), 66% were male, with a mean age for the overall sample of 68·3 years (SD ± 12·5 years). The vast majority of survivors were retired (66·7%), although almost a fifth were working full time before the onset of the stroke (19·8%), which in most cases occurred either secondary to a cardioembolism (42·0%) or due to unknown aetiology (24·7%). Approximately four-fifths of survivors were classified as mildly to moderately disabled according to the mRS (76·5%), with approximately one-fifth classified as moderately to severely disabled (23·5%). Fifty-three percent of survivors were classified as cognitively impaired according to the MoCA scale (MoCA ≤26), with a mean score of 24·0 (SD ± 4·6). Approximately half of the survivors were classified as vulnerable (51·8%), with mean VES scores of 4·3 (SD ± 4·0). Almost a third (30·7%) of survivors were classified as anxious, and 20·9% showed depressive symptoms at six-months, with mean HADS scores of 5·5 (SD ± 4·7) and 4·3 (SD ± 3·6), respectively.

Profile of primary caregivers

The majority of primary caregivers were female (75·3%) and the wives (49·4%) of stroke survivors; 91·3% of primary caregivers were members of the stroke survivors' immediate family, and almost all caregivers lived with others (96%). These data are presented in Table 1.

Prior to stroke onset, approximately 15% of caregivers looked after survivors, as they required some level of help with daily living. This rose to approximately three-fifths of caregivers following stroke onset (59·3%).

Table 1 Profile of ASPIRE-S caregiver sample

n = 162	Total *n* = 162 (100%)
Mean age (years)	59·4 (SD ± 15·3)
Relationship status	
Married	129 (79·6%)
Single	22 (13·6%)
Widowed	3 (1·9%)
Separated	4 (2·5%)
Divorced	3 (1·9%)
Partner	1 (0·6%)
Relationship to patient	
Husband	25 (15·4%)
Wife	80 (49·4%)
Son	11 (6·8%)
Daughter	25 (15·4%)
Brother	1 (0·6%)
Sister	6 (3·7%)
Friend	1 (0·6%)
Neighbor	1 (0·6%)
Partner	8 (4·9%)
Other	4 (2·5%)
Living arrangements	
Lives alone	6 (3·8%)
Lives with others	152 (96·2%)
Dependence of stroke patient	
Fully independent	66 (40·7%)
Requires a little help	66 (40·7%)
Requires a lot of help	25 (15·4%)
Fully dependent	5 (3·1%)
Mean scores	
Satisfaction levels	44·2 (SD ± 15·8)
HADS-A scores	5·9 (SD ± 4·7)
HADS-D scores	3·6 (SD ± 3·8)
VES scores	1·1 (SD ± 1·9)

HADS-A/D, Hospital Anxiety and Depression Scale-Anxiety/Depression; SD, Standard deviation; VES, Vulnerable Elders Survey.

Effects of caring on caregivers

Quantitative analysis of the UK Healthcare Commission National Patient Survey of Stroke Care showed that only 8·6% of primary caregivers were very satisfied with service provision received, while almost 90% of primary caregivers reported some level of dissatisfaction: 53·5% of caregivers were moderately satisfied, indicating some areas of dissatisfaction, and 37·9% of caregivers were moderately dissatisfied. No caregivers reported being very dissatisfied.

Three general questions on overall satisfaction were asked at the end of the 'Carer Satisfaction with Care' section of the caregiver questionnaire. While the majority of caregivers were satisfied to some extent overall, approximately one-quarter of primary caregivers indicated that they were dissatisfied/very dissatisfied with both the information received from the hospital (33%) and the help and support received since coming home (24·2%), while 23·9% of primary caregivers were dissatisfied with the information received from the community.

According to the HADS, greater than one-third of primary caregivers were classified as anxious (31·3%), while almost one-fifth was classified as depressed (18·3%).

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Table 2 Unadjusted logistic regression analyses for the relationship between elevated levels of anxiety and depression and caregiver distress

	Anxious carers *HADS-A > 8)*			Depressed carers *HADS-D > 8)*		
Variable	Odds ratio	*P* value	95% Confidence intervals	Odds ratio	*P* value	95% Confidence intervals
Anxious carer				5·07	0·001	1·89–13·60
Depressed carer	5·07	0·001	1·89–13·60			
Dissatisfied carer	2·78	0·085	0·87–8·87	3·21	0·106	0·78–13·24
Vulnerable carer	4·03	0·023	1·22–13·34	16·38	<0·001	4·58–58·52
Carer age-group (≥65)	0·83	0·161	0·65–1·08	1·10	0·572	0·80–1·50
Carer gender (Female)	1·59	0·316	0·64–3·92	0·64	0·364	0·25–1·67
Anxious patient	3·47	0·010	1·35–8·93	4·41	0·006	1·53–12·72
Depressed patient	5·17	0·002	1·83–14·58	6·91	0·001	2·26–21·17
SS mRS	1·46	0·380	0·63–3·38	2·19	0·104	0·85–5·65
SS cognitive impairment (MoCA)	2·35	0·049	1·00–5·51	2·21	0·130	0·79–6·17

HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment at six-months (≤26); mRS, modified Rankin Scale at six-months(≥3); SS, stroke survivor.

A minority of caregivers were themselves classified as vulnerable according to the Vulnerable Elders Survey (11·5%).

Profile of caregivers exhibiting anxious and depressive symptoms

Of the caregivers exhibiting anxious symptoms, 80% were female, and of those exhibiting depressive symptoms, two-thirds were female. The majority of caregivers exhibiting psychological distress were the spouses of stroke survivors (67·5% for anxious symptoms, 70·8% for depressive symptoms). Moderate to high levels of dissatisfaction with service provision were exhibited by 52·6% of caregivers with anxious symptoms, as was the case for the majority of caregivers exhibiting depressive symptoms (60·0%). Almost one-half (47·4%) of caregivers exhibiting depressive symptoms and 21·6% of caregivers exhibiting anxiety were classified as vulnerable. Thirteen caregivers exhibited both anxiety and depressive symptoms, and 63·6% were classified as vulnerable.

In this analysis, there were no relationships between age of caregiver, gender of caregiver, or other demographic variables and presence of anxious or depressed symptoms in univariable logistic regression. Table 2 shows logistic regression analysis, which showed stroke survivor anxiety (OR = 3·47, $P = 0·010$), stroke survivor depression (OR = 5·17, $P = 0·002$), stroke survivor cognitive impairment (OR = 2·35, $P = 0·049$), and caregiver vulnerability (OR = 4·03, $P = 0·023$) to be significantly related to caregiver anxiety. Caregiver vulnerability (OR = 10·62, $P = 0·001$), stroke survivor anxiety (OR = 4·41, $P = 0·006$), and stroke survivor depressive symptoms (OR = 6·91, $P = 0·001$) were also significantly related to caregiver depressive symptoms. The logistic regression analyses demonstrated no significant relationships between carer age group, gender, dissatisfaction with care, or stroke survivor disability (mRS) – and caregiver anxiety or depressive symptoms.

Discussion

This study on the implications for caregivers of informal caregiving of stroke survivors identified substantial levels of anxious and depressive symptoms among the caregivers, as well as evidence of significant dissatisfaction for some with community and hospital services. Previous literature has identified that caregivers are indeed at increased risk of anxiety and depression (10,25) and that many are dissatisfied with the services provided to them (7,8). However, this was the first study which attempted to quantify this dissatisfaction as a means by which relationships could be established between dissatisfaction and emotional distress.

Stroke survivor anxiety, depressive symptoms, cognitive impairment, and quality of life were significant predictors of caregiver anxiety and depressive symptoms six-months poststroke. This is in line with existing literature, which identifies relationships between negative behavioral and psychological symptoms as well as poor quality of life among stroke survivors with increased risk of anxiety and depressive symptoms amongst caregivers (10,13). Cognitive impairment among stroke survivors appeared to be a significant predictor of caregiver anxiety, which is also in line with existing research (13). This study also demonstrated an already established relationship between stroke severity and caregiver depression (10).

Two highly important and relatively unresearched relationships were identified through this study, the first being the relationship between higher caregiver vulnerability scores and higher levels of caregiver anxiety and depressive symptoms. Vulnerability, as measured by the VES, increases (by at least 20%) the risk of death and functional decline (26). This decline in physical function, in conjunction with a potential decline in mental health, may place not only caregivers, but also stroke survivors, in an increasingly vulnerable position, especially in the context of existing research which shows that caregiver well-being can affect stroke survivor rehabilitation outcomes, and that there exists interdependence between caregiver and stroke survivor mental health (27). Secondly, increased levels of dissatisfaction with service provision among the caregivers were significantly associated with increased levels of both anxiety and depressive symptoms. As substantial levels of dissatisfaction with care have been noted among Irish and international populations of stroke survivors (2,8), it would be wise for health and community services to improve

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the support provided to caregivers, especially in light of this relationship.

In contrast with some existing literature, caregiver demographic factors did not emerge as independent predictors of either caregiver anxiety or depressive symptoms (10,13). This may be explained by the study's relatively small sample size, which was the major limitation of this study. It is likely that a larger sample size of primary caregivers would have resulted in more statistical power to further explore other potentially important relationships. The relatively small sample size, along with the fact that the majority of stroke survivors assessed had mild to moderate stroke severity, limited the generalizability of these results. However, as there is little study of this particular subject, we believe these results add to the literature in this field.

Another limitation was the lack of use of objective measures of caregiver health. There is very little research on physical health outcomes of caring for stroke survivors. Due to the close relationship between psychological and physical health (28,29), it would be beneficial for future research to focus on objective measures as indicators of caregiving effect. Literature on caregiving in dementia has shown increased salivary cortisol levels amongst this group (30), and thus, cortisol levels may prove to be a useful measure in future research. Urinary catecholamines and blood pressure levels have also been used as objective measures of health in the general population and could potentially be useful here (31). Furthermore, this study examined emotional distress using only two measures: anxiety and depressive symptoms. Emotional distress also encompasses caregiver burden and caregiver psychological stress levels. These two factors are important to overall quality of life and well-being, and have been used as further measures of emotional health in existing literature (32,33). It would therefore be advisable for further studies to use a wider base of emotional distress measures to create a more comprehensive profile of the psychological effects of caregiving in the context of stroke.

Finally, it must be noted that the prevalence of anxiety and depressive symptoms among this study's caregiver population was similar to that of its stroke survivor population. Furthermore, some studies on caregivers of patients with different neurological disorders, such as dementia and chronic mental illness, showed lower levels of anxiety and depression than those seen in this study's caregiver population (34,35). Stroke survivor caregivers play a key role in patient rehabilitation, and it is therefore necessary to safeguard their psychological well-being by identifying possible ways to decrease their burden and thus increase positive rehabilitation outcomes of stroke survivors. While stroke survivors are usually given the majority of attention, it is essential that health services, both hospital and community based, take caregiver emotional health and satisfaction into consideration.

Findings indicate the importance of both identifying vulnerability in caregivers as well as addressing their dissatisfaction with care, as both dissatisfaction and vulnerability are potential risk factors for poor emotional outcomes in caregivers and, thus, poorer stroke outcomes in stroke survivors. Future research should address the development of early interventions to maximize optimal outcomes for both.

Acknowledgements

We acknowledge the ASPIRE-S Steering Group members: Professor Hannah McGee, Royal College of Surgeons in Ireland; Professor Emer Shelley and Professor Ronan Conroy, Royal College of Surgeons in Ireland; Professor Peter Kelly, Mater Misericordiae University Hospital, Dublin; and Dr Eamon Dolan, Connolly Hospital, Dublin.

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