


Caregiver's Recall of Stroke Discharge Education Exceeds Patients and Is Associated With Greater Satisfaction

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Abstract

Stroke survivors and their caregivers report not receiving enough information at discharge. To identify strengths and weaknesses of stroke discharge education, we delivered questionnaires that assessed patient and caregiver recall, perceived utility, and satisfaction at discharge as well as 1- and 3-month follow-up. Categorical data of responses were compared between time periods using Fischer exact test. Recall significantly differed between discharge (86%) and 1-month follow-up (54%, $P < .05$), but not discharge and 3-month follow-up (69%). Patient perceived utility at both 1 month (69%) and 3 months (64%) was lower than at discharge (92%, $P < .05$). Patient satisfaction was lower at 1 month (69%) and 3 months (54%) than discharge (92%, $P < .05$). Caregiver recall declined from discharge (81%) to 1 month (65%) but improved from 1 to 3 months (82%, $P < .05$). Caregiver satisfaction and perceived utility remained positive through the study. The results suggest stroke patients and their caregivers suffer from education recall failure over time that is associated with worse satisfaction and perceived utility by patients. Reinforcement at 1 month may improve caregiver recall. We conclude that education for caregivers may be more reliably reinforced, suggesting a role in continued patient education.

Keywords

discharge education, education recall, ischemic stroke, depression

Introduction

The ability of patients to recall instructional education influences their medical compliance and related clinical outcomes (1). Ebbinghaus forgetting curve demonstrates a logarithmic decline in recall, with a plateau at 30 to 90 days past the acquisition of information (2). Elderly populations show greater deficits in information retention compared to younger groups due to a natural decline in episodic and working memory capacities (3). Cerebrovascular disease affecting prefrontal white matter is thought to disrupt cognitive circuits and also contribute to the occurrence of late-life depression (4). Accordingly, depression occurs at increased frequency following stroke and is associated with impaired memory formation (5,6). White matter lesions in particular are associated with treatment-resistant, chronic depression (4). Stroke patients, therefore, are at risk of recall atrophy due to age and cerebrovascular sequela.

Accordingly, stroke survivors and their caregivers report inadequate discharge education. Educational reinforcement

for patients and caregivers improves their understanding and satisfaction (7). For example, patient satisfaction is improved by caregiver-mediated interventions and reinforcement of stroke education in the follow-up period (7,8). Education reinforcement via telephone coaching for patients has also been studied and discussed as a potentially useful and underexplored tool; however, existing literature lacks the power to detect clinical utility (9). Despite associated improvements in patient recall and satisfaction, interventional strategies aimed at improving education recall have only been marginally correlated with improved clinical outcomes (7–10).

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Per institutional experience, despite discharge education, stroke patients report a weak understanding of the mental health sequelae after stroke, particularly depression. Conversely, caregivers reported greater understanding, thus promoting consideration of having caregivers play a strategic role in reinforcing patient discharge education. To further study these observations, we developed questionnaires assessing discharge education recall, satisfaction, and perceived utility and delivered them throughout the poststroke follow-up period to both patients and caregivers. We hypothesized a positive relationship between stroke discharge education retention, satisfaction, and perceived utility throughout the poststroke follow-up period, and we predicted patients would demonstrate a greater decline in all 3 assessments compared to their caregivers.

Methods

Design and Study Participants

This study included all patients admitted for ischemic stroke to a tertiary care center assessed to be alert and oriented to person, place, and time at discharge by an attending neurologist (D.S.). Additional deficits in either communication (eg, receptive aphasia) or cognition that prohibited reliable completion of questionnaires were grounds for exclusion per the attending neurologist's discretion (D.S.). Caregivers were selected by the enrolled patient and included per voluntary response. Patient demographics (ie, age, sex, and ethnicity) were collected at the time of enrollment. Ethical and clinical approval to perform this study was obtained from the institutions review board (IRB; Study00001442 and Study00001441).

Fifty consecutive stroke patients were considered for study inclusion. Twenty were not alert and oriented ($\times 3$) or had deficits (eg, aphasia), preventing reliable questionnaire completing. Six declined to participate. Twenty-four patients (13 males, 11 females) and 19 caregivers (6 males, 13 females) were enrolled in the study. Five patients designated themselves as their own caregiver and were not included in the caregiver analysis. Participants were Caucasian except for 1 Native American patient, reflective of the surrounding rural population. Ages ranged from 62 to 91 for patients and 45 to 88 for caregivers. All enrolled participants consented to follow up questionnaires in person at discharge and by phone call at 1-month and 3-month postdischarge.

Data Collection and Analysis

Individual questionnaires were developed for patients and caregivers. The patient questionnaire was designed to assess mental health outcomes, particularly depression, due to the observation of patient's deficit in recall regarding related discharge education. Assessment of other educational objectives was limited to minimize patient cognitive overload during discharge. Conversely, institutional observations were less robust regarding caregiver education retention,

which therefore prompted a more explorative assessment. The caregiver questionnaire included similar assessments of mental health outcomes to the patient questionnaire. Questions for both patients and caregivers were designed to assess recipient recall, perceived utility, and satisfaction of discharge education (Supplementary Appendix A). The institution's trained stroke coordinator (BSN registered nurse [RN], stroke certified RN, and neurology certified RN) delivered discharge education and directed delivery of follow-up questionnaires. Discharge education entailed an oral presentation and discussion of material contained within a patient handout (Krames—"After a stroke: a guide for stroke recovery and prevention").

At discharge, paper questionnaires were handed out by the stroke coordinator and completed in person. The 1-month and 3-month follow-up questionnaires were delivered via phone call (C.H., C.B., K.R., B.M., J.C., and J.H.) using standardized phone scripts (Supplementary Appendix B). Researchers were not aware of participant responses to prior questionnaires at either the 1-month or 3-month follow-up. Comparative analyses of discharge education retention, perceived utility, and satisfaction were performed by categorizing responses as "positive" or "negative" (Supplementary Appendix C). A Fisher exact test was used to compare the responses at discharge, 1-month, and 3-month follow-up.

Results

Patient Questionnaire

Responses to the patient questionnaire are listed in Table 1. At discharge, 24 patients completed the questionnaire, 13 of which responded at both the 1-month and 3-month follow-up. At 3-month follow-up, 62% of responders were the same as those responding at 1-month follow-up. There were significant differences in patient recall between discharge and 1 month, but not discharge and 3 months. Both perceived utility and satisfaction were significantly lower than discharge at 1 and 3 months. The difference between 1 and 3 months was not significant for any assessment.

Caregiver Questionnaire

Responses to the caregiver questionnaire are listed in Table 2. At discharge, 19 caregivers completed the questionnaire, 14 of which responded at 1-month follow-up and 11 at 3-month follow-up. At 3-month follow-up, 73% of responding caregivers were the same as those responding at 1-month follow-up. There was a significant decline in caregiver recall from discharge at 1 month, but not 3 months. Further, there was a significant improvement in recall from 1 to 3 months. Neither caregiver's perceived utility nor satisfaction varied significantly from discharge through follow-up.

Table 1. Positive Responses to Patient Questionnaire.^a

	Discharge	1 Month	3 Months
General (%)			
Previous diagnosis of depression	3 (13)	3 (23)	3 (23)
Receiving treatment for depression	5 (22)	3 (23)	3 (23)
Present depression concern	5 (22)	4 (31)	4 (31)
Recall (%)			
Increased risk of depression	21 (88)	8 (62)	9 (69)
Depression related education	22 (92) ^b	6 (46) ^b	9 (69)
Combined	43 (86) ^b	14 (54) ^b	18 (69)
Utility (%)			
Understanding depression	23 (96)	9 (69)	9 (69)
Recognizing signs of depression	22 (92)	9 (69)	10 (77)
Understanding depression treatment	24 (100) ^{b,c}	9 (69) ^b	6 (46) ^b
Combined	69 (92) ^{b,c}	27 (69) ^b	25 (64) ^c
Satisfaction (%)			
Depression-related education	24 (100) ^{b,c}	9 (69) ^b	7 (53) ^c

^aSignificance differences ($P < .05$) indicated by matching superscripts letters (b and c).

Table 2. Positive Responses to Caregiver Questionnaire.^a

	Discharge	1-Month	3-Month
General (%)			
Direct family member	17 (89)	13 (93)	11 (100)
Live in same household	13 (68)	7 (50)	6 (55)
Recall (%)			
Type of stroke	18 (95) ^{b,c}	7 (50) ^b	6 (55) ^c
Stroke education	18 (95)	13 (93)	11 (100)
Mental health education	15 (79)	9 (64)	8 (82)
Stroke prevention education	18 (95)	12 (92)	11 (100)
Patient support groups	12 (63)	6 (42)	9 (82)
Caregiver support groups	11 (58)	8 (57)	9 (82)
Combined	92 (81) ^b	55 (66) ^{b,c}	54 (82) ^c
Utility (%)			
Medication management	19 (100)	13 (93)	11 (100)
Therapy assistance	17 (89)	13 (93)	11 (100)
Stroke prevention	19 (100)	13 (93)	11 (100)
Stroke recognition	16 (84)	9 (64)	7 (64)
Combined	58 (78)	40 (77)	36 (81)
Satisfaction (%)			
Discharge education	18 (95)	13 (100)	11 (100)

^aSignificance differences ($P < .05$) indicated by matching superscript letters (b and c).

Discussion

Our results show that stroke education retention follows Ebbinghaus forgetting curve, with significantly worse recall at 30 days and no further decline by 90 days compared to discharge for both patients and caregivers. Contrary to Ebbinghaus predictions, responses suggested an improvement in recall from 30 to 90 days, although this difference

was only significant in caregivers. Variance in which participants responded at 1 month versus 3 months could have played a role in this divergence. However, analysis of the trend in responses between 1-month and 3-month follow-up shows that the percentage of responses reflecting loss of recall among patients that differed between time periods remained consistent across the study for both the patient and caregiver cohorts.

Literature has indicated that (1) caregiver-directed patient care and education is correlated with improved outcomes, (2) spaced reinforcement improves satisfaction, and (3) telephone coaching may be a viable method of spaced education reinforcement (8–12). We suggest that caregivers may be more responsive to telephone coaching than patients. The 1-month follow-up questionnaire may have served as spaced, repetitious reinforcement, a strategy correlated with greater satisfaction in previous studies, and this could explain the improvement in recall (8,10). It is the authors' experience that caregivers in particular would cite the 1-month questionnaire as the reason for responding positively to recall questions at 3 months when they had previously responded negatively at 1 month.

The discordance in patient and caregiver recall ability may be associated with the decline in neuroplasticity known to accompany psychiatric sequela of stroke (eg, depression) (13). These observations, along with the significant improvement in caregiver recall from 1-month to 3-month follow-up, suggest caregivers are more responsive to spaced education reinforcement than stroke patients and could serve as a reliable method of continued patient education.

In addition to recall, patients demonstrated a significant loss in satisfaction and perceived utility of discharge education. Due to limitations of the study, this relationship is only supported as correlation; however, we suggest it may be causative, as shown in previous research. Other possibilities are that the discharge education itself was inadequate or patients overestimated their understanding of education at discharge. Conversely, caregivers demonstrate high satisfaction and perceived utility of discharge education that did not differ significantly through the 3-month follow-up period.

Future works may explore if the improved recall and satisfaction of caregivers could be transferred to patients by encouraging an active role for caregivers in the reinforcement of patient discharge education. Additionally, caregivers' confidence in caring for patients could supplement the patients' perceived unhelpfulness of discharge education. Finally, some patients were without caregivers at discharge or follow-up. Identifying programs to connect patients with potential caregivers could benefit patients following ischemic stroke.

Limitations

This study is limited by a small sample size and high attrition rate. Unanswered phone calls prevented successful follow-up. Patients were especially difficult to reach and

often caregivers were contacted to make a connection with the patient. Differences between group demographics (caregivers were younger and more female as a group) may have impacted study outcomes. The nonuniformity of questionnaires limits direct comparisons between patients and caregivers. The questionnaires did not cover all topics discussed during discharge education and therefore the data may not be representative of discharge education as a whole. Retrospectively, the respective education level of patients and caregivers was of interest, but it was not considered until data collection period was closed and further means of acquiring such information were not described in the IRB. Additionally, the sources and methods used to deliver discharge education at this study's institution may vary from other stroke centers. The lack of intended intervention limits claims that spaced education reinforcement improves outcomes.

Conclusion

Stroke patients' ability to recall discharge education in the follow-up period suffers significant decline, correlated with a lower satisfaction, and perceived utility for discharge education. Although caregivers demonstrate a similar atrophy of recall, they may be more responsive to spaced reinforcement of discharge education in the follow-up period and demonstrate stable discharge education satisfaction and perceived utility. Telemedicine and phone calls to caregivers have been studied as a potential means of improving postdischarge patient care. In certain populations with known cognitive deficits, such as stroke patients, targeting of caregivers via telemedicine and phone call coaching may be more efficacious than direct patient contact.

Implications

Utilizing caregivers as a means of delivery for education reinforcement may improve stroke patients' recall, satisfaction, and perceived helpfulness of discharge education. Policies incorporating caregivers into patient education and reinforcement of that education in the follow-up period may therefore improve patients' outcomes. Future research on caregiver-mediated interventions for patient stroke education would further elucidate these concepts.

Authors' Note

Caleb J. Heiberger led the study design, data acquisition and analyses, and drafting of the manuscript. Clayton Busch, John Chandler, Kevin Rance, Brett Monteith, Josh Hanscom, and Gauravjot Sandhu assisted in the study design, data acquisition and analyses, and drafting of the manuscript. Divyajot Sandhu mentored the project and assisted in the study design, data acquisition and analyses, and drafting of the manuscript.

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Supplemental Material

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