



Original Research

Effects of Peer Mentoring for Caregivers of Patients With Acquired Brain Injury: A Preliminary Investigation of Efficacy



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KEYWORDS

Brain injuries;
Caregivers;
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Abstract *Objective:* To evaluate effectiveness of a peer mentor intervention for caregivers of patients with acquired brain injury (ABI) in encouraging caregiver participation in support services to prepare them for the role of caregiving and in reducing caregiver stress and depression. *Design:* Controlled trial with participants randomized to either usual care or 1-to-1 visits with a family caregiver peer mentor during the ABI inpatient rehabilitation stay. *Setting:* Nonprofit rehabilitation hospital specializing in care of persons with brain and spinal cord injury. *Participants:* Caregivers (N=36) of patients with ABI admitted for rehabilitation whose discharge location was home with care provided by family members (caregivers: 93% female; 58% White; mean age, 48±10.4y). *Interventions:* One-to-one peer mentoring visits during the inpatient stay with a trained peer mentor who is also a family caregiver of a survivor of brain injury. *Main Outcome Measures:* Frequency of participation in support services for family caregivers, reported caregiver stress, and reported caregiver depressive symptoms. *Results:* There was no difference between groups in participation in support services for family caregivers. Participants in the peer mentor intervention group reported significantly greater improvement in caregiver stress at discharge and 30 days post discharge than participants in the usual care group. Reported depressive symptoms were also lower for the intervention group, but change scores did not achieve statistical significance at discharge or 30-day follow-up.

List of abbreviations: ABI, acquired brain injury; CI, confidence interval; COVID-19, coronavirus disease 2019; KCSS, Kingston Caregiver Stress Scale; MD, mean difference; PHQ-9, Patient Health Questionnaire 9; US, United States.

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Conclusions: Peer mentoring appears to improve caregivers' ability to handle the stress of caregiving and reduces reported depressive symptoms. There was no between-group difference noted in participation in support services for families; however, participation was adversely affected by restrictions imposed during the coronavirus disease 2019 pandemic, which may have masked any effect.

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Acquired brain injury (ABI) is a significant cause of long-term disability. In the United States (US), about 85,000 individuals annually who sustain a traumatic brain injury will experience functional limitations requiring lifelong care and support.^{1,2} Nearly 1.1 million survivors of stroke have lasting difficulty in performing basic activities of daily living.³ An estimated 16% of US households are affected by family members with ABI.⁴

Over 80% of survivors of ABI with injuries requiring hospitalization will be discharged home,⁵ many with significant care and supervision needs resulting from physical and cognitive impairments.^{6,7} Family members often must take on the responsibility of providing long-term care, resulting in high levels of caregiver burden, psychological distress for the caregiver, and increased likelihood of unplanned hospital readmissions for survivors of ABI.⁸⁻¹² Researchers have consistently reported disruptions in family functioning of survivors of ABI, with wives and mothers most often taking on the caregiving responsibilities.¹³ Studies suggest that caregivers of survivors of ABI experience chronically high levels of stress compared with caregivers of other populations.^{14,15}

The problem of caregiver stress and lack of preparation for caregiving is widely acknowledged.⁸⁻²⁴ Evidence points to the long-term adverse effect of caregiver stress/burden on both patient and caregiver,^{16,17} yet health systems serving patients with ABI struggle to find effective strategies to prepare and support family caregivers before and during the transition back to community. Once the patient returns home, the opportunity for preventive interventions is often lost because of funding limitations, logistical issues, and disengagement with the health system.

During the inpatient stay and in preparation for discharge, information and instruction is provided to families about how to care for their loved ones once home. However, family caregivers are often overwhelmed and their ability to process information significantly diminished. Many factors contribute to this diminished capacity, but a key issue is the family's lack of acceptance of their loved one's injury and subsequent care needs. Transformative learning theory helps explain why families may resist efforts to learn the knowledge and skills needed to effectively manage their loved one's care needs at home.²⁵ It is the process by which individuals transform how they think about the future after a major life event (ABI). This transformation in perspective helps regain meaning in life and is important to achieving "new normal" after a life-altering event.²⁵ Peer support—learning from others who have gone through a similar experience—is a strong component of efforts to promote transformative learning.^{26,27}

The family's ability to cope with stress can influence the quality of support they provide to their loved one and,

consequently, the extent of the recovery of the survivor of ABI.²⁰⁻²⁴ Families vary in how they cope with the stress and burden of caregiving. Effective problem solving can decrease anxiety and depression for caregivers.²⁸ Caregivers with greater self-efficacy in managing their loved ones' care needs report being better equipped to cope with the demands of caregiving.^{29,30} Peer-to-peer support has also shown to improve self-efficacy in care management resulting in improved health outcomes.^{31,32}

This research was undertaken at a private, nonprofit hospital specializing in neurorehabilitation of patients with ABI and spinal cord injury. The hospital admits approximately 350 patients annually for comprehensive inpatient rehabilitation after ABI. Almost 90% of patients are discharged home after the inpatient stay and over 80% in the care of family members. The ABI unit provides extensive education and support services for families to prepare them for the caregiving role post discharge. These services include nurse-directed training in specialized care routines based on patient needs (eg, bowel and bladder management, tube feeding, medication management), behavioral and psychological counseling to help cope with patients' behavioral and emotional changes, discharge planning and transition support (eg, assistance with locating needed resources locally), and peer support opportunities including peer-led self-management training to promote caregiving self-efficacy.

Even with this rich array of services, it is often difficult to engage families during the inpatient stay because of the overwhelming consequences of their loved one's injury. Because transformative learning has not occurred in response to the injury, family caregivers do not yet understand or accept the long-term and potentially permanent nature of the patient's care needs, the complexity of continuing medical care, the changing family dynamics and roles of family members (caregivers, "bread winners"), the financial effect of ongoing medical costs and lost productivity of family members, and other consequences of the injury. In an effort to improve engagement of family members in the available caregiver support services, we established a family caregiver peer mentoring program to provide 1-to-1 support and advisement to family members. Our hope was that interaction with peers who have experienced the transition into the role of caregiver would promote transformative learning and encourage family caregivers to take advantage of needed supports and assistance during and after the inpatient stay. In doing so, we hoped to ease caregiver stress and burden as well as improve outcomes for both caregivers and patients. Thus, the purpose of this research was to evaluate effects of 1-to-1 peer mentoring on caregiver participation in family support resources and on caregiver outcomes of stress and depression.

Methods

Design

We conducted a randomized trial to compare effects of peer mentoring to usual care on the outcomes of participation in family caregiver training and support opportunities, caregiver-reported stress and burden, and caregiver-reported depressive symptoms. The research protocol and study materials, including informed consent form for participants, was approved by the hospital's institutional review board prior to initiation of the study.

Participants

We targeted an enrollment of 60 participants based on available funding for this preliminary efficacy study. Our previous research of a similar peer mentor intervention for patients with traumatic spinal cord injury indicated a moderate effect size ($d=0.48$) for the effect on self-efficacy.³³ The "pwr" package in R indicates that a sample of 64 is sufficient to achieve statistical power of 80% at a significance level of .05 for a 2-sample *t* test with an expected medium effect size.

Eligible participants were family caregivers of patients admitted to the ABI inpatient rehabilitation unit with an expected discharge to home with family members. In 2020, a total of 303 of 344 patients (88%) admitted for inpatient rehabilitation were discharged home with family caregivers. Participants were recruited, via in-person visits or email, by the study's research coordinator (A.M.). The study was explained to prospective participants, and those interested in participating were asked to provide written informed consent.

Those who provided consent were enrolled then randomized to either the peer mentoring intervention or to usual care, described below. We used an online calculator (www.graphpad.com) to generate a randomization schedule, which was maintained by a research staff member not directly involved in the study. Once a participant was enrolled, the research coordinator contacted the noninvolved staff member to receive the participant's group assignment.

Interventions and comparators

The peer mentoring intervention was delivered by the hospital-employed peer support team and volunteer peer mentors. The peer support team (2.5 full-time equivalent

appointments split between 3 family caregivers of former patients with ABI) recruited 9 additional family caregivers of former patients with ABI to serve as volunteer mentors. These volunteers provided a range of mentors with varying demographic characteristics to better match with study participants.

Volunteer mentors completed an online peer mentor training and certification course modeled after the program developed by the Christopher and Dana Reeve Foundation and described in a previous publication.³³ Completion of hospital volunteer training, including a background check, was also required. Certified volunteer mentors then underwent peer mentor orientation and training (2-3h) with the peer support program manager. After individual training, each new mentor shadowed a staff mentor (member of the peer support team) for at least 3 mentor visits.

Intervention group participants received an initial consult with a member of the peer support team and were assigned a peer mentor (staff or volunteer) based on the patient's injury characteristics and the caregiver's demographic characteristics (age, sex, relationship to patient, additional interests). Each primary mentor might be supplemented by other staff or volunteer mentors, as needed, to meet specific caregiver needs. A peer mentor met with the participant at least weekly throughout the inpatient stay and for up to 30 days post discharge.

Study participants determined the topics covered during the peer mentor visits. As part of training, peer mentors were instructed in use of motivational interviewing techniques to build rapport and help guide caregivers in the choice of topics related to their questions and concerns about caring for their injured family member. Detailed records were kept of topics covered in all mentoring sessions. Topics are summarized in [table 1](#), also noting the number and percentage of participants who discussed each topic during at least 1 mentoring session. Many topics, particularly in the first 3 categories (caregiving role, patient recovery, adjustment/emotional management) were covered in more than 1 mentoring session.

Participants randomized to usual care received the usual discharge planning and family support services offered by the ABI program (described previously). These services include nurse instruction in care routines, case management support for discharge, peer support services, referral to family counseling and community services as indicated, and general information resources about brain injury. Participants in both the intervention and usual care groups also had access to the online peer support community created for ABI caregivers (facebook.com/shepherdabi.peers). In addition, usual care participants could request 1-to-1 visits

Table 1 Topics covered in peer mentoring sessions

Topic	Caregivers, n (%)
Caregiving role, care management, changing family dynamics	18 (100)
Patient functional recovery, self-care, return to school/work, recreation, driving	18 (100)
Adjustment, emotional management, coping skills, hope	17 (94)
Transition home, discharge planning, community reentry, community resources, social services, and benefits	17 (94)
Health, medical, home health services	14 (78)
Patient behavior and mood, home/community safety, drug/alcohol use	11 (61)
Finances, travel, housing assistance	9 (50)

with peer mentors, and, indeed, 14 of 18 usual care participants (78%) received at least 1 peer mentoring visit.

Outcome measures

We examined 3 primary outcomes: (1) participation in family support services; (2) caregiver stress and burden (Kingston Caregiver Stress Scale [KCSS]³⁴); and (3) caregiver depressive symptoms (Patient Health Questionnaire 9 [PHQ-9]³⁵). The KCSS and PHQ-9 were administered at the time of enrollment in the study (preintervention), within 72 hours of discharge from the inpatient rehabilitation program (discharge), and approximately 30 days post discharge (follow-up). Both instruments were administered at each time point during a telephone interview between the primary caregiver and a trained interviewer.

Participation in family support services was documented by monitoring attendance at all such meetings, training sessions, and education classes. These activities include orientation classes for new families, support groups, and self-management classes offered by the peer support team. Some of these activities are offered once to family members during the inpatient stay (eg, orientation class) and others are offered weekly (eg, support groups), so activities could be attended multiple times. All family caregivers were encouraged to participate, but attendance was not mandatory.

Study interruption because of coronavirus disease 2019 pandemic

We initiated study enrollment on February 4, 2020, and discontinued enrollment on March 13, 2020, because of coronavirus disease 2019 (COVID-19) restrictions (eg, dramatically curtailing visitors in the hospital). Prior to implementation of COVID-19 restrictions, all family and peer support services were offered in person, and 1-to-1 mentoring visits were completed in person or by phone. We reinitiated study enrollment on June 1, 2020, and the final 30-day follow-up data collection call was made on January 28, 2021. Once study activities resumed, all group training and support services for families and all 1-to-1 peer mentoring visits were conducted by phone, video call, or web conference.

Results

Figure 1 presents the Consolidated Standards of Reporting Trials diagram outlining study enrollment. Of 169 admissions during the study enrollment period, 148 (88%) met inclusion criteria. Of these eligible candidates, 44 (30%) declined participation and research staff were unable to contact 47 candidates (32%), in part because of restricted access in response to COVID-19. An additional 8 candidates agreed to participate but were unable to initiate the study because of interruptions in service required by COVID-19 restrictions. As a result, 49 participants were successfully enrolled in the study, 25 randomized to the intervention group and 23 to usual care. Only 41 participants completed both baseline and discharge data collection and 36 (18 each intervention

and usual care group) were successfully contacted for 30-day follow-up data collection. The results below pertain to the 36 participants completing 30-day follow-up.

Table 2 summarizes demographic characteristics of study participants and patients in each of the 2 comparator groups. There were no significant differences between groups for either patients or caregivers; only differences in race approached statistical significance ($P=.063$), with a greater percentage of White participants in the intervention group (81% White) than the usual care group (50% White).

Participation in family support services

Participants in the intervention group attended a total of 46 activities (mean=2.6, SE=0.738) compared with 63 activities (mean=3.5, SE=1.10) for the usual care group. Mean difference between groups in participation was not significant ($P=.482$). Of note, 15 of 36 participants (42%) did not attend any of the family support services offered. Nonparticipation was higher for the intervention (50%) than the usual care group (33%) and also notably higher after the study resumed (50%) compared with the pre-COVID-19 period (29%).

Caregiver stress and depressive symptoms

For the outcome measures of caregiver stress (KCSS) and depressive symptoms (PHQ-9), we calculated 2 change scores: discharge minus preintervention and 30-day follow-up score minus preintervention score. After calculating the change scores, we computed independent sample *t* tests for mean differences to compare changes in preintervention with discharge and preintervention with 30-day follow-up reported stress and depressive symptoms for each group. Figure 2 presents the average and SE of scores on the KCSS for each group at each data collection interval. The cut point between mild and moderate stress on the KCSS is also indicated. There were no statistically significant differences between groups on KCSS scores preintervention ($P=.169$; mean difference [MD]=2.89; 95% confidence interval [CI], -1.2 to 7.1). Statistically significant differences between groups were noted in change scores for both comparisons: (1) preintervention to discharge ($P=.002$; MD=6.5; CI, 2.5-10.5; $d=1.09$) and (2) preintervention to 30-day follow-up ($P<.001$; MD=8.06; CI, 3.9-12.2; $d=1.33$).

Figure 3 presents the average and SE of PHQ-9 scores for each group at each data collection interval. The cut point between mild and moderate depression on the PHQ-9 is also indicated. There were no significant differences between groups on PHQ-9 scores preintervention ($P=.269$; MD=1.61; CI, -1.3 to 4.5). No statistically significant differences between groups were noted in change scores for either comparison: (1) preintervention to discharge ($P=.257$; MD=1.61; CI, -1.2 to 4.5) and (2) preintervention to 30-day follow-up approached statistical significance ($P=.093$; MD=2.44; CI, -0.4 to 5.3).

Discussion

We hypothesized that exposure to 1-to-1 peer mentoring would be associated with (1) increased participation in

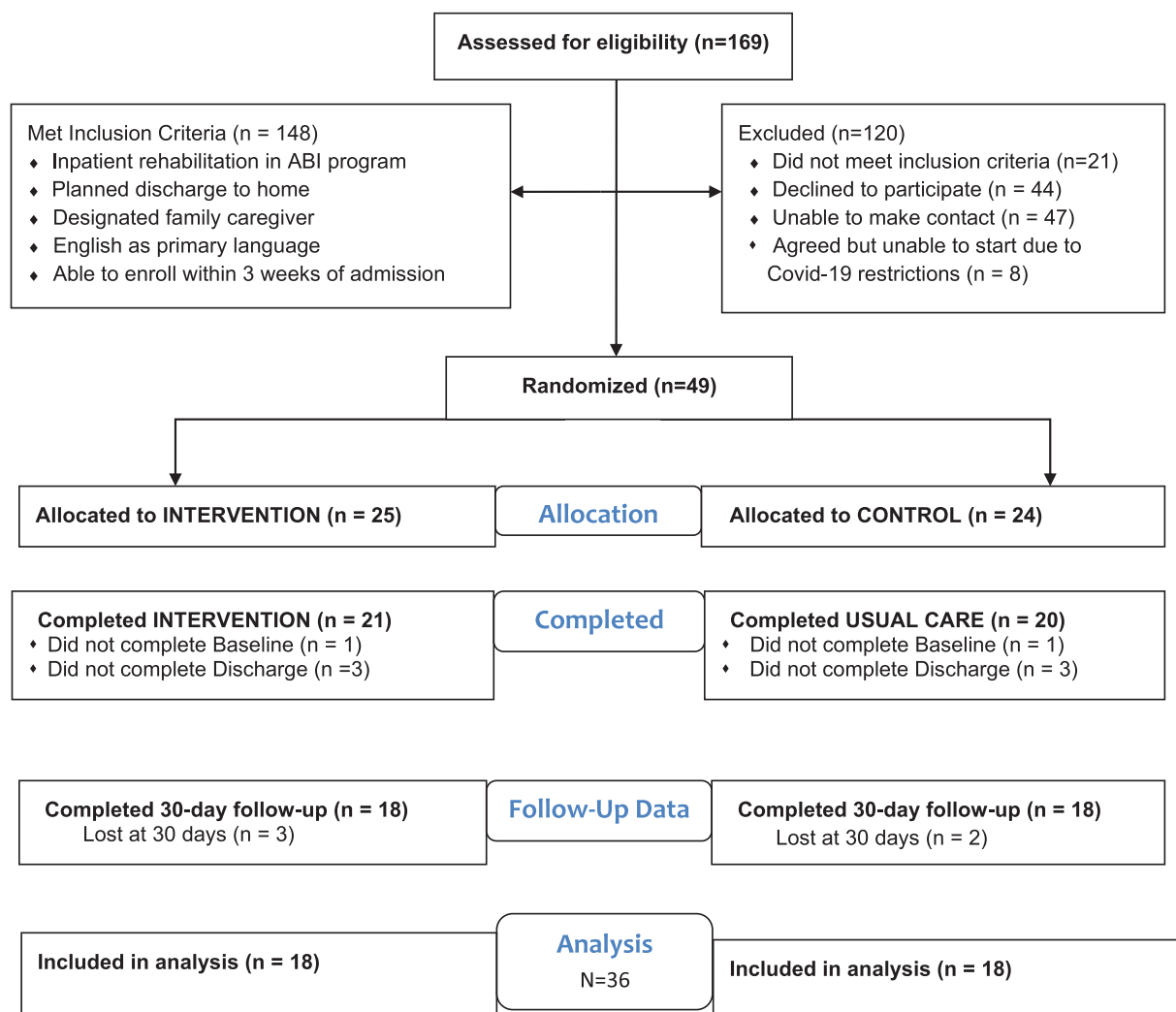


Fig 1 Consolidated Standards of Reporting Trials flow diagram.

family support services to prepare for caregiving; (2) lower reported caregiver stress and burden; and (3) fewer reported depressive symptoms. We based these hypotheses on the assumption that exposure to peers would promote transformative learning, help family members understand the importance of preparation for the new role of caregiving, and may ease stress, burden, and depression associated with these major life changes.

We observed no significant difference between groups in levels of participation in family support services. However, we did note a dramatic reduction in participation by all participants after restrictions were imposed because of the COVID-19 pandemic. These restrictions included severe limitations on visitation in the hospital by family members and transition from in-person to virtual (phone or video) meetings and communications between family, clinicians, and peers. It is likely that curbs on visitation negatively affected participation because fewer family members were present in the hospital. It is also possible, but not verifiable, that family members found virtual participation less appealing than in-person participation. We were not able to confirm this with family members who chose to not participate. However, feedback from those who did participate in the

virtual peer visits and support services suggested high levels of satisfaction, meeting if not exceeding satisfaction with in-person contacts. This finding suggests that any perceived lack of appeal for virtual participation was not borne out by those who did participate.

The finding that participation in peer mentoring was associated with a significant reduction in caregiver stress at both discharge and 30 days post discharge is very encouraging, particularly given that participants in both groups reported moderate levels of stress at all outcome measurement intervals. Stress of caregiving is known to increase over time.^{24,36,37} Although not verifiable in the present study, any reduction in stress for caregivers in the peer mentoring group is thus likely to have an additive effect over time, potentially improving health outcomes for both the patient and caregiver. Further research is needed to replicate the relationship between peer mentoring, lower caregiver stress, and confirm the long-term benefits associated with stress reduction.

Further research is also needed to better understand why peer mentoring may be effective in reducing caregiver stress. There is ample evidence from previous research suggesting that peer-to-peer interventions are effective in

Table 2 Demographic characteristics of study participants (N=36)

Characteristic	Experimental (n=18)	Control (n=18)	Significance Test (t or χ^2 test)	P Value
Traumatic, n (%)	11 (61.1)	11 (61.1)	$\chi^2=0.00$	>.99
Severe, n (%)	3 (18.8)	2 (11.1)	$\chi^2=0.63$.237
Disorder of consciousness, n (%)	1 (6.3)	0 (0.0)	$\chi^2=0.54$.368
Length of stay (d), mean \pm SD	58.2 \pm 6.08	53.5 \pm 6.46	t=0.53	.602
Age (y), mean \pm SD	43.4 \pm 15.9	40.3 \pm 16.5	t=0.57	.570
Male, n (%)	15 (93.8)	12 (75)	$\chi^2=2.13$.144
White, n (%)	13 (81.3)	8 (50)	$\chi^2=3.46$.063
Caregiver				
Age (y), mean \pm SD	48.3 \pm 9.73	47.3 \pm 10.8	t=0.28	.785
Male, n (%)	1 (6.3)	1 (6.3)	$\chi^2=0.00$	>.99
Relationship			$\chi^2=4.24$.119
Parent, n (%)	4 (22.2)	7 (38.9)		
Spouse, n (%)	14 (77.8)	8 (44.4)		
Other family member, n (%)	0 (0.0)	3 (16.7)		
Payor source, n (%)			$\chi^2=0.66$.719
Private insurance	17 (94.4)	15 (83.3)		
Medicaid	1 (5.6)	2 (11.1)		
Other	0 (0.0)	1 (5.6)		

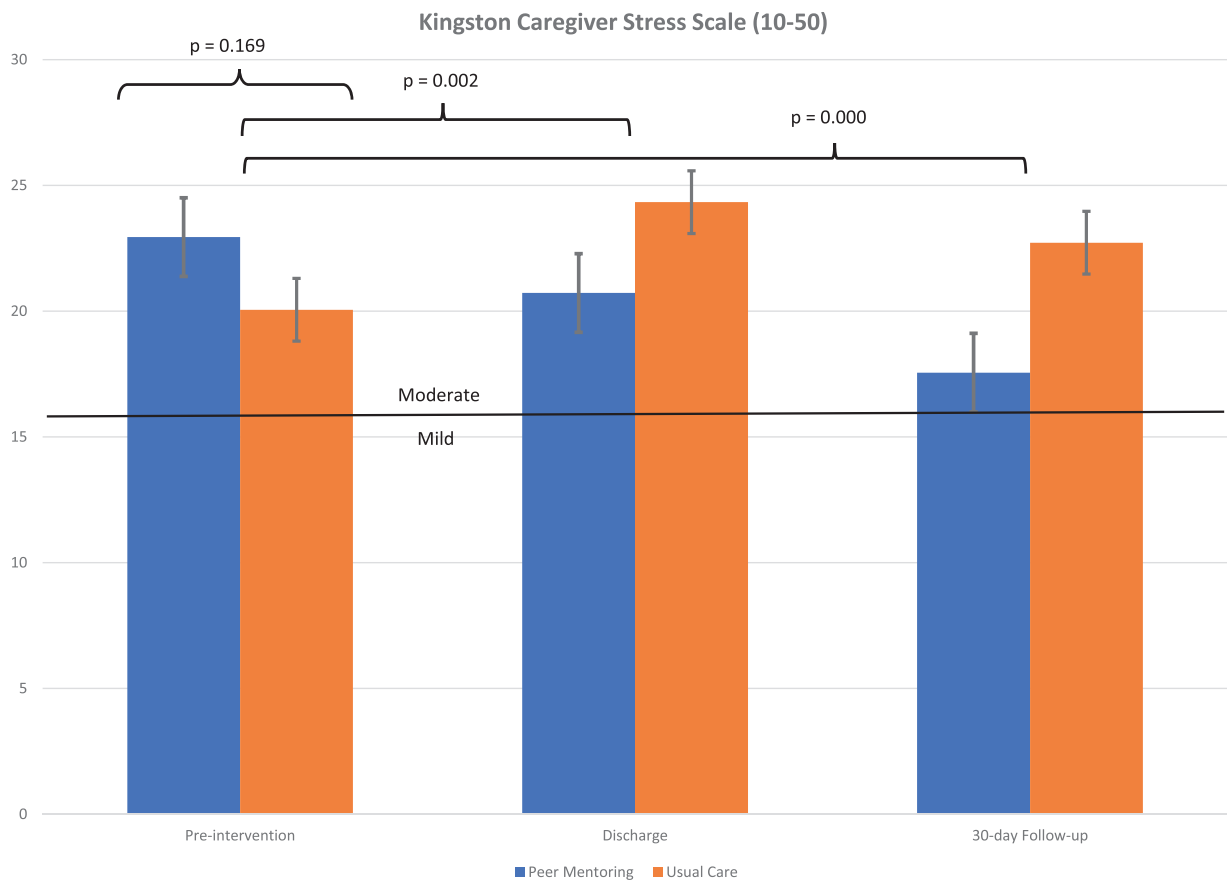


Fig 2 Results for KCSS.

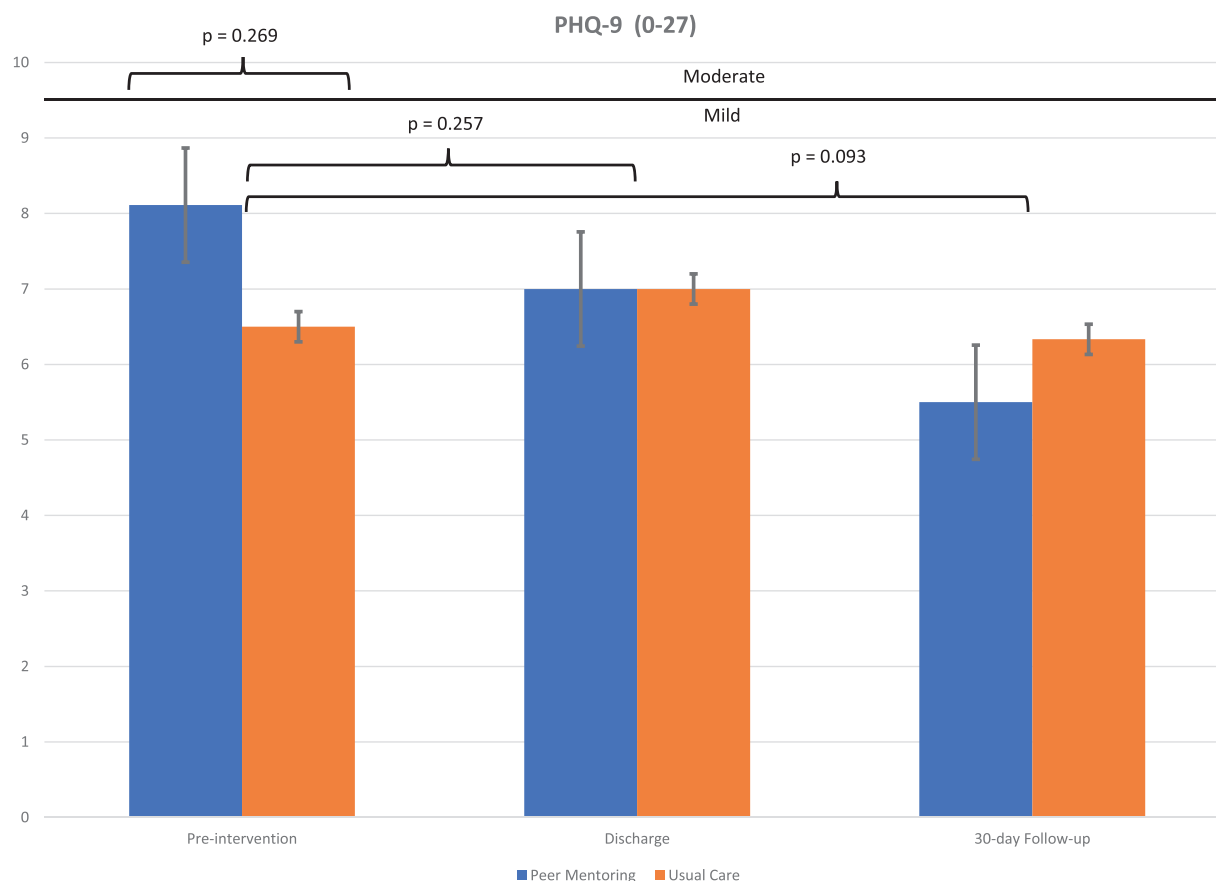


Fig 3 Results for PHQ-9.

improving self-efficacy in care management and health outcomes.^{32,33} It stands to reason that improved self-efficacy may contribute to reduced caregiver stress. Although it is beyond the scope of the present study to verify this relationship, feedback from study participants offers support for this relationship.

We solicited feedback from participants in the peer mentoring intervention group via a follow-up survey to gain insights into how and why the intervention might have been effective in reducing caregiver stress. We received responses from 11 of 18 intervention group participants. Only 1 participant indicated that peer mentoring was not helpful in managing caregiver-related stress. This caregiver reported having few interactions with the peer mentor because her husband had a very short stay and nearly complete recovery from his brain injury (thus low caregiver stress). As for reasons the intervention might be effective, common responses included having someone to reach out to with questions/concerns, helping to understand what might be coming in the future, and the relief of talking to someone who could relate personally to the fears, concerns, and emotions experienced by the caregiver.

Survey respondents were asked how much they believed the peer mentoring intervention improved overall confidence in their caregiving abilities. All but 1 respondent reported being confident or very confident in their abilities, and all respondents reported that mentoring did improve their confidence in caregiving. Moreover, all respondents

reported they would recommend the peer mentor intervention for other families. Finally, in response to the question about what participants would want to share about their experience, many reported on the value of the program, especially having a diverse pool of mentors so they could be matched with someone with similar interests, values, racial and ethnic background, and caregiver experiences.

The finding of no statistically significant relationship between peer mentoring and reduction in depressive symptoms is unexpected, but depression levels for caregivers in both groups were rated as mild at all data collection time points. Depression scores were lower for both groups 30 days post discharge than at admission and discharge. This finding may reflect the positive effect of the combination of support services provided to families to ease the burden of transition home post discharge. Further research is needed to verify the finding of lower depression over time and confirm that it is indeed a trend, not a spurious result of this preliminary study.

Study limitations

The most notable limitation of the present study was not achieving the desired sample size because of restrictions imposed by the COVID-19 pandemic. In addition to not enrolling our desired sample, the rate of dropouts and those lost to follow-up was much higher than expected, with only 73% of enrolled participants completing all aspects of the

study. Many of these losses were unavoidable because of disruptions brought on by COVID-19. Despite the overall effect of COVID-19, we were able to complete the study with a sample size sufficient to demonstrate very large effect sizes for the relationship between peer mentoring and caregiver stress, as measured by changes from preintervention to discharge ($d=1.09$) and preintervention to 30 days post discharge ($d=1.33$). This speaks to the potential strength of the intervention, a finding that must be tempered by the need to replicate in a subsequent study, conducted without the “noise” introduced by COVID-19.

Conclusions

We evaluated the effects of 1-to-1 peer mentoring offered to family caregivers of patients with ABI during the acute phase of recovery, intending to demonstrate that peer mentoring would increase families’ participation in services to prepare them for the role of caregiving and subsequently reduce overall caregiver stress, burden, and depressive symptoms. Possibly affected by restrictions brought on by the COVID-19 pandemic, we were unable to demonstrate any effect on caregiver participation, and, in fact, lower overall participation by all caregivers was observed post COVID-19. We found a powerful relationship between peer mentoring and lower caregiver stress but little effect on reported depressive symptoms. Participants reported mild depression, but our follow-up interval was only 30 days post discharge. This interval was too brief to detect the longer-term negative effect of caregiver stress and burden or subsequent positive differences associated with the peer mentor intervention. These findings, although limited by the small scale of the study, suggest positive benefits from 1-to-1 mentoring and support further study to confirm and expand knowledge of its positive effects.

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