



Original Research

Feasibility Study of Problem-Solving Training for Care Partners of Adults With Traumatic Brain Injury, Spinal Cord Injury, Burn Injury, or Stroke During the Inpatient Hospital Stay



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KEYWORDS

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Caregiver;
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Stroke

Abstract Objective: To determine the feasibility of delivering an evidence-based self-management intervention, problem-solving training (PST), to care partners of individuals with traumatic brain injury (TBI), spinal cord injury (SCI), burn injury, or stroke during the inpatient hospital stay.

Design: In this single group pre-post intervention pilot feasibility study.

Setting: Inpatient rehabilitation or acute care and community.

Participants: Care partners (spouse or partner, family member, friend who is in any way responsible for the health or well-being of the care recipient) of individuals with TBI, SCI, burn injury, or stroke (N=39).

Intervention: PST is a metacognitive self-management intervention that teaches individuals a global strategy for addressing self-selected problems. Participants received up to 6 sessions of PST in person or via telephone during their care recipient's inpatient stay.

List of abbreviations: CaPPS, Care Partner Problem Solving; CSQ, Client Satisfaction Questionnaire; PRPS, Pittsburgh Rehabilitation Participation Scale; PST, problem-solving training; SCI, spinal cord injury; TBI, traumatic brain injury; WAI, Working Alliance Inventory. Supported by the Foundation for PM&R Midcareer Investigator Research Grant Award (PI: S.B.J.), the Agency for Healthcare Research and Quality (grant no. HS022418), and Clinical and Translational Science Awards National Institutes of Health (grant no. UL1TR001105). Disclosures: none.

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Main Outcome Measures: We measured feasibility of recruitment, intervention delivery, and postintervention use of a smartphone app (Care Partner Problem Solving [CaPPS]) and participant satisfaction (Client Satisfaction Questionnaire [CSQ]) and engagement (Pittsburgh Rehabilitation Participation Scale [PRPS]) with the intervention.

Results: Of 39 care partners approached, $n=10$ (25.6%) were ineligible. Of $n=29$ (74.4%) who were eligible, $n=17$ (58.6%) refused, and $n=12$ (41.4%) consented, of whom $n=8$ (66.7%) completed ≥ 3 PST sessions. Not perceiving any benefit was the most common reason for refusal, followed by no interest in research. Participants were very satisfied with PST (CSQ mean = 3.35, SD = 0.60), reported strong working alliance (Working Alliance Inventory mean = 6.8, SD = 3.1), and demonstrated very good engagement (PRPS mean = 4.75, SD = 1.41). CaPPS was downloaded and used by only $n=3$ participants.

Conclusions: Delivering a self-management intervention to care partners during the care recipient's acute hospital stay is feasible for a subset of potential participants. Short lengths of stay, language fluency, and perceiving no potential benefit were noted barriers. Boosters via smartphone app have potential, but several barriers must first be overcome.

The United States Census Bureau estimates that nearly 58 million people currently live in the United States with a disability,¹ and more than 65 million people in the United States provide informal care to an individual with a chronic illness or disability.² Knowledge about the experiences of these informal caregivers, or care partners, predominantly comes from dementia literature. Data from the National Health and Aging Trends Study and the National Study of Caregiving revealed that care partners of older adults who provide substantial help with health care are significantly more likely to experience emotional, physical, and financial difficulty than care partners providing no help.³ They are 5 times more likely to experience participation restrictions in valued activities and 3 times more likely to experience work productivity loss.³ They also have a higher risk for problematic alcohol use if they experience social and emotional burden related to caregiving.⁴ A systematic review concluded that interventions to reduce care partner stress may reverse the negative effect of caregiver burden.⁵

Care partners supporting individuals with sudden onset medical conditions like traumatic brain injury (TBI), spinal cord injury (SCI), burn injury, or stroke share many of the same experiences as care partners of those with dementia. However, unlike care partners of adults with dementia, they have no warning or preparation for their new caregiving roles. The unpredictable and sudden onset of these conditions introduces unique considerations regarding the timing and setting of intervention delivery, but little research focuses on these care partners, despite the high prevalence of these conditions.

Currently in the United States, more than 5 million (~2% of the US population) are living with TBI-related disability,⁶ ~282,000 have SCI-related disability,⁷ up to 50% of individuals with burn injury experience associated disability,⁸ and ~7 million people have stroke-related disability.⁹ Individuals with disability related to traumatic injury or stroke experience numerous and often lifelong changes that require ongoing support, including changes in mobility, cognition, emotion, and sensation,^{7,8,10-22} but access to rehabilitation and mental health services in the community for individuals with these chronic conditions is limited.^{6,20,22-24} As a result, it often falls to care partners to provide the support required,

despite limited or no caregiver training. Care partners must also manage their own lives and their complex relations with their care recipients.^{25,26}

Care partners of adults with traumatic injuries and stroke frequently report high levels of caregiver burden, which may lead to depression, anxiety, and physical symptoms, as well as reduced quality of life.^{17,24,25,27-33} Caregiver burden is largely predicted by care partners' unmet needs.^{29,30,34-36} Because the effects of traumatic injury and stroke continue to change over time, so do the perceived needs of care partners.^{17,23,24,28,35,37} Over time, care partners report increasing difficulty meeting their needs, particularly as problems occur in the absence of any professional support. Interventions should therefore address not only current care partner needs, but also needs that may arise over time, particularly as individuals transition out of formal care settings.^{23,38} Care partners of adults with burn injury specifically indicated that family adjustment after injury is a long-term issue that should be addressed early in the inpatient hospital stay.^{17,25} However, care partner self-management interventions to date tend to occur in an outpatient setting.³⁹

Self-management interventions may address care partner needs over time by providing care partners with the skills necessary to manage and adapt to challenges over time. Self-management refers to the skills collectively applied to achieve a physically and emotionally health life, including a sense of autonomy and perceived control, the ability to engage in healthy behaviors, employing a problem-solving approach to address needs, readiness to change, and self-efficacy.⁴⁰⁻⁴² Self-management skills are essential for translating knowledge into action. Problem-solving theories, especially D'Zurilla's social problem-solving model, emphasize how critical problem solving is for effective self-management.⁴³ Formal problem-solving training (PST) could provide the requisite skills for care partners to independently translate the health education they receive into realistic and effective action after hospital discharge.

Problem-solving training (PST)⁴⁴ is a self-management intervention that teaches individuals a simple, systematic method for evaluating problems, generating and selecting solutions, developing specific goals and action plans, and

evaluating and revising plans as needed. Individuals learn to set achievable goals under the coaching of a therapist and gain self-efficacy as they see that problems that may have overwhelmed them are indeed solvable when approached in a stepwise, rational fashion. PST thus helps to circumvent impulsive or unrealistic problem-solving attempts that lead to failure, discouragement, and feelings of helplessness. There is a growing body of literature supporting PST for reducing distress among care partners of individuals with acquired disabilities.^{39,45-52} In 4 randomized controlled trials (RCTs), PST was delivered predominantly via telephone to care partners of adults with TBI or stroke, beginning as early as 1-week post-hospital discharge. All 4 trials showed greater reduction in depression or emotional distress among care partners receiving PST compared to a control group, and 3 trials demonstrated greater reductions in maladaptive problem solving.⁴⁵⁻⁴⁸ Similarly, 3 RCTs of PST for care partners of adults with SCI or severe disabilities reported improvements in problem solving over time, with 2 also noting decreased depressive symptoms.^{50,51,53} In 1 trial demonstrating efficacy, care partners were provided only 3 sessions of PST and education, with brief telephone contact over the first year of caregiving.⁵¹

Together, these studies suggest that PST skills can potentially be acquired with few sessions and maintained over time. However, most studies did provide ongoing contact over time, which may be necessary for long-term maintenance. The growing ubiquity of smartphones⁵⁴ presents unique opportunities for effective and easily scalable approaches to maintain or *boost* the effects of PST after formal training is complete, but no study to date has examined the use of mobile technologies to promote generalization and maintenance of PST.

The purpose of the current study was to assess the feasibility of delivering PST to care partners of adults with new onset of traumatic injuries or stroke during the care recipient's inpatient rehabilitation (or in the case of burn injuries, acute care stay). This included measuring feasibility of recruitment, reasons for ineligibility and refusal to participate, number of PST sessions completed during the inpatient stay, and care partner satisfaction and confidence with PST. Our secondary purpose was to explore the feasibility of using a smartphone app—the Care Partner Problem Solving (CaPPS) app—for 8 consecutive weeks after the final PST session. We hypothesized that care partners would complete at least 3 intervention sessions prior to care recipient discharge and would report high satisfaction and confidence with the PST intervention.

Methods

Overview and design

We conducted a single-group feasibility study of PST for care partners of adults with TBI, SCI, burn injury, or stroke, delivered during the care recipient's acute inpatient rehabilitation or acute care stay. A research coordinator administered baseline assessments in person prior to the study intervention. A trained interventionist delivered up to 6 sessions of PST to care partners during the care recipient's inpatient hospital stay. After discharge, participants were given the opportunity to download the CaPPS app, which provided *booster* sessions once per week for 8

weeks (app content was hosted by *ilumivu*⁵⁵). During the final intervention session, the interventionist assessed the participant's confidence using the PST strategy. Participant satisfaction and perceived working alliance were assessed at 1-month postdischarge via electronic survey through REDCap. The University of Texas Southwestern Medical Center Institutional Review Board approved all research procedures, and we obtained written informed consent from all participants.

Participants

Participants were care partners of individuals with TBI, SCI, burn injury, or stroke admitted to an Academic Medical Center hospital. Care partners were defined as individuals involved in assisting the care recipient with activities of daily living and/or medical tasks or responsible in any way for the care recipient's well-being after hospital discharge. Recruitment occurred through flyers, physician referrals, or by approaching care partners of patients recruited for the North Texas TBI Model Systems at UT Southwestern or the UT Southwestern Burn Model Systems studies. Inclusion criteria were (1) care partner (spouse, partner, family member, friend) of an individual admitted to the hospital with a new onset TBI, SCI, burn injury, or stroke; (2) ≥ 1 -year relation with the care recipient; (3) fluent in English; (4) ≥ 18 years old; (5) capacity to self-consent; and (6) owned a smartphone. Exclusion criterion was as follows: (1) legal dispute over care partner's role in the care of the care recipient.

Measures

We collected demographic (age, sex, race, ethnicity, education) data and care partner relation information (nature, duration, living status, relation quality) at baseline to characterize the sample. Feasibility data included all of the following measures: (1) number and percentage of recruited participants; (2) reasons for ineligibility; (3) reasons for refusal; (4) number of sessions completed; (5) length of sessions; and (6) Pittsburgh Rehabilitation Participation Scale (PRPS)⁵⁶ rated by interventionists after each PST session to measure participant engagement in the intervention. The PRPS is a 6-point scale validated for completion by a rehabilitation therapist to measure engaging, with ratings ranging from 1 (No engagement) to 6 (Excellent engagement); (7) intervention uptake (participant confidence applying the PST strategy rated from 0 to 10; number of sessions it took for the participant to feel confident that they could use the PST strategy) assessed by the interventionist during the final PST session; (8) Client Satisfaction Questionnaire-8 (CSQ-8)⁵⁷ at 1 month post-discharge to measure participant satisfaction with PST. The CSQ-8 is a validated self-reported measure of satisfaction with health-related services received. It includes 8 questions rated on a 4-point scale, yielding a single summed score; and (9) Working Alliance Inventory (WAI)⁵⁸ at 1-month postdischarge to measure the participant's perceived working alliance with the interventionist. The WAI is a validated self-reported 12-item measure of how the participant feels about the interventionist, with

individual items measured on a 7-point scale and summed for a total score.

PST intervention

PST is a global or metacognitive strategy training approach (ie, a strategy for how to problem solve rather than a strategy for solving a specific problem), grounded in self-management theory, that teaches a global problem-solving strategy linked to an simple mnemonic: ABCDEF (A=assess the problem, B=brainstorm, C=consider and choose, D=develop and do, E=evaluate, F=flex).⁵⁹ Participants apply this strategy to whatever problems they choose to address, under the guidance of the interventionist. The PST intervention consisted of up to 6 sessions (~30-45min each) following a structured format, previously described.^{59,60} Participants received these sessions either in person or via telephone during the care recipient’s inpatient hospital stay, with a target of 2-3 sessions per week. The final session consisted of PST strategy review, review of progress made, and discussion of applying the PST strategy to problems that may arise in the future; this final session could be completed after discharge, if not completed before. Use of the PST strategy within and between sessions occurred through structured PST worksheets provided to the participants. The 2 study interventionists were students in a Clinical Masters in Rehabilitation Counseling program. They were trained and supervised in PST delivery by the study PI (a PhD-trained certified rehabilitation counselor), after a training protocol previously described.⁶⁰

CaPPS app development and content

Two consumer focus groups conducted in October 2017 elicited 5 consistent preferences regarding app design and content for mobile health apps in general. Notable to CaPPS design were the following 3: (1) ability to communicate with health care providers; (2) cognitive strategies, including a notification system; and (3) app accessibility and privacy. Based on this consumer feedback and structured around the content of the PST intervention, we developed the initial CaPPS app (fig 1) using ilumivu’s mobile app platform.⁵⁵ CaPPS sent notifications to participants to complete weekly booster sessions consisting of the following: Goal Attainment Scaling⁶¹ to evaluate goal attainment each week, Patient Health Questionnaire-2,⁶² Alcohol Use Disorders Identification Test-Concise,⁶³ Zarit Burden Interview-4,⁶⁴ and 2 subscales from the Brief Coping Orientation to Problems Experienced (Brief COPE) Inventory.⁶⁵ Participants also had the opportunity through free text in the app to describe the problem(s) they applied the PST strategy to over the past week, and were given the option to review the steps of PST through the app.

In July 2018, we conducted 2 focus groups, one with clinicians and the other with individuals with acquired brain injuries and their family members to beta test the CaPPS app. Five themes emerged through these groups: (1) the app is easy to use; (2) notifications are a helpful memory aid; (3) participants liked the ability to track and share data with health care providers; (4) the wording in some of the assessments could be clearer; (5) participants desired the ability to track their responses and monitor progress over

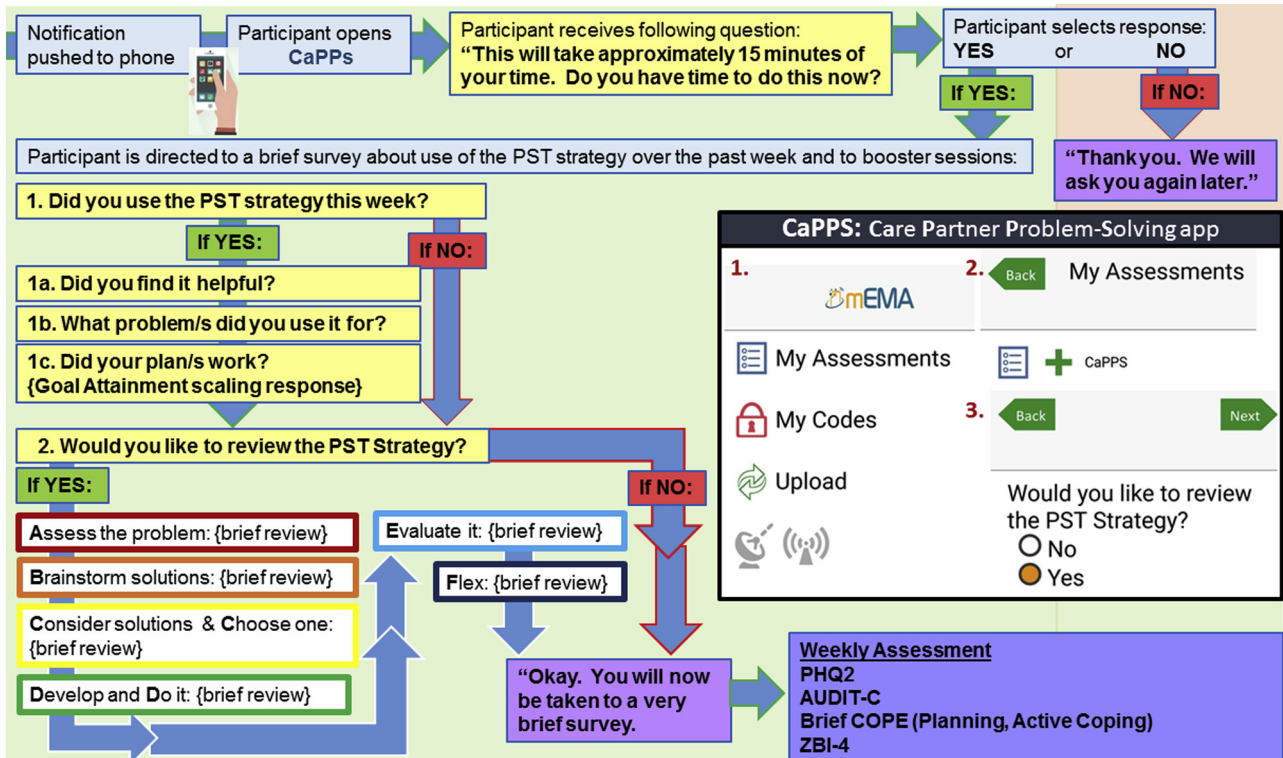


Fig 1 CaPPS smartphone app design.

time; and (6) clinicians felt that data from the app could be used to inform inpatient rehabilitation services.

We also created instruction sheets that detailed step-by-step instructions for downloading and using the app, specific to Android or iOS operating system, including screenshots for each step and a trouble-shooting guide for common problems experienced when using the app. Participants downloaded the *ilumivu* app for free from the mobile app store, then entered a unique mobile code (assigned by investigators) linking the app to the research study. Participants were then sent notifications weekly for 8 weeks prompting them to use the CaPPS app.

Statistical analysis plan

For our first aim, we descriptively report the number and percentage of recruited participants, reasons for ineligibility, reasons for refusal, and number of PST sessions completed. We present summary statistics (means, standard deviations) of participant satisfaction with PST, perceived working alliance with the interventionist, and participant confidence using PST. For our second aim, to assess initial feasibility of using a smartphone app to *boost* a behavioral intervention for care partners, we present number of participants who downloaded and used CaPPS.

Results

Feasibility of recruitment and intervention delivery

Between July and October 2018, we approached 39 care partners for potential participation in this study, of which

12 consented to participate. [Figure 2](#) provides further detail on reasons for ineligibility or refusal. [Table 1](#) presents demographics characterizing the study sample. All consented participants had known their care recipient for more than 10 years, though only 41% were living with the care recipient. Compared to all approached participants, those who consented were less often women and more often white and non-Hispanic. Of those who consented, 10 participants completed at least 1 PST session, with 8 completing 3 or more sessions (see [fig 2](#)). One participant withdrew after starting the intervention; all others completed their 1-month follow-up assessment.

Participants (n=11) were generally very satisfied with the intervention (CSQ mean=3.35, SD=0.60, 1- to 4-point scale). Interventionists rated participants who completed at least 1 PST session (n=10) as having very good engagement, on average, across all sessions (PRPS mean=4.75, SD=1.41, 1- to 6-point scale). Seven participants rated their level of confidence in their ability to apply the PST strategy after completion of the intervention as 9 (SD=1.5) on a 10-point scale, with higher scores indicating greater confidence. On average, they felt confident using the PST strategy after only 2.6 (SD=1.3, range=1-4) sessions. Participants reported a strong working alliance with interventionists (WAI mean=6.8, SD=3.1, 0- to 7-point scale).

CaPPS

Mobile app profiles were created for 9 participants. This included a profile for a participant who did not complete any PST sessions, but who was sent the instructions for

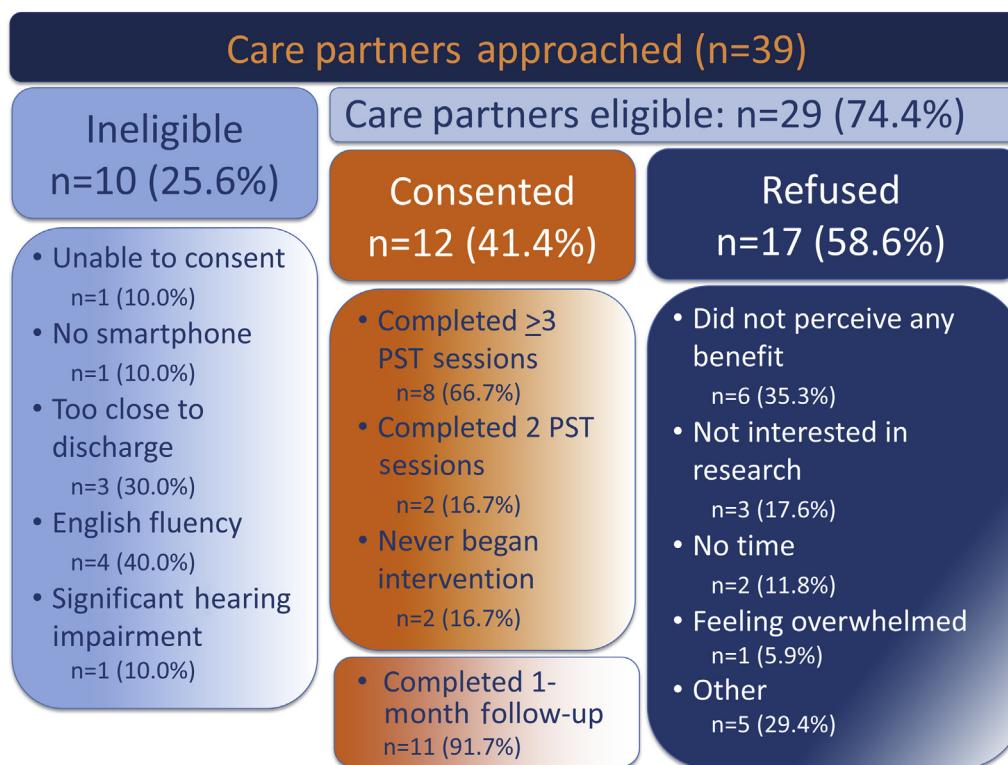


Fig 2 Flow chart for feasibility, intervention delivery, and follow-up assessment for PST for care partners of adults with traumatic injuries and stroke during the care recipient's inpatient hospital stay.

Table 1 Participant characteristics

	All Potential Participants N=39	Consented Participants n=12
Consent status		
Ineligible	10 (25.6)	
Consented	12 (30.8)	
Refused	17 (43.6)	
Demographics		
Mean age \pm SD (y)	49.5 \pm 14.6	49.4 \pm 9.7
Sex (Women)	32 (82.1)	8 (66.7)
Education		
Less than high school	-	1 (8.3)
High school graduate	-	6 (50)
College graduate	-	5 (41.7)
Race		
White	28 (71.8)	10 (83.3)
Black	9 (23.1)	2 (16.7)
Unknown	2 (5.3)	0 (0)
Ethnicity		
Hispanic	13 (33.3)	2 (16.7)
Non-Hispanic	17 (43.6)	6 (50)
Unknown	7 (17.9)	4 (33.3)
Relation to care recipient		
Parent	6 (15.4)	3 (25)
Spouse	16 (41)	4 (33.3)
Child	8 (20.5)	3 (25)
Sibling	5 (12.8)	1 (8.3)
Other family	3 (7.7)	1 (8.3)
Friend	1 (2.6)	0 (0)
Diagnosis of care recipient		
TBI	8 (20.5)	3 (25)
SCI	4 (10.3)	1 (8.3)
Burn injury	7 (17.9)	3 (25)
Stroke	20 (51.3)	5 (41.7)
Living with the care recipient	-	5 (41.7)

Data are n (%) or as otherwise indicated.

downloading and using CaPPS via e-mail. We later decided not to create profiles for participants who did not complete PST sessions ($n=3$). Of the 8 participants who completed PST sessions and were assigned user profiles, 3 completed the on-demand booster session (available whenever they chose to open it) 8 times collectively, and 1 participant completed the weekly booster session twice in response to the notifications. Notably, we initially introduced the app during the final PST session, but switched to introducing the app in the second to last session as the study went on, providing additional contact time to problem-solve app use with participants.

Discussion

The feasibility and efficacy of early PST for care partners during the care recipient's inpatient hospital stay are unknown. As a first step in addressing this gap in knowledge, we examined the feasibility of delivering PST to care partners of adults with new onset traumatic injuries or

stroke during the care recipient's inpatient rehabilitation or acute care stay.

Of all eligible care partners we approached, about two-fifths consented to participate. The most common reason for refusal was not perceiving any likely benefit. Participation rates could potentially be improved by providing a brief, plain language summary of the evidence for the benefits of PST for care partners or providing quotes or brief testimonials of individuals who went through the intervention. Notably, all participants who consented had a high school diploma or college degree, which may suggest an education-related volunteer bias, though we do not have education information for unconsented individuals. A small number was not interested in any research; they may have been more interested in PST if it was available as an intervention embedded in existing clinical programs (as opposed to a research study). Despite the acute-care period often being an overwhelming and busy time for care partners, only 3 potential participants refused because they felt overwhelmed or had no time. The most common reason for ineligibility was lack of English language fluency (all fluent in Spanish), supporting the need for translation and adaptation of PST into Spanish. The next most common reason for ineligibility was the care recipient having a scheduled discharge within 48 hours, leaving no time to start the study. For this study, we focused on completing PST sessions prior to the care recipient's discharge. Future work should examine starting the intervention prior to discharge and continuing across the transition of care, which would allow for more care partners to participate despite short lengths of stay.

Once enrolled in the PST study, our data supported the general feasibility of intervention delivery; that is, we were mostly able to deliver the intervention as planned. Failure to complete 6 sessions was due predominantly to short lengths of the stay. One participant did elect to discontinue the intervention, stating only that he no longer wished to participate. Continuing the intervention across the transition of care from the hospital to home would circumvent the problem of short lengths of stay, while still initiating the intervention earlier for care partners. Previous work supports the efficacy and feasibility of delivering PST via telephone to care partners of individuals with disabilities shortly after care recipient discharge.^{46,51} In our study, participants found the intervention to be very satisfactory, demonstrated through their direct reports of satisfaction and through their high level of engagement during the PST sessions. Participants also reported a high level of confidence using PST, even after receiving only 2-3 sessions. A strong working alliance, a participant-reported measure of the strength of the working relation between the interventionist and participant, indicated that interventionists built the necessary rapport and conveyed respect to participants. To quote 1 participant: "I saw the relevance after the initial meeting...It was helpful for me to break down my goals as I was stressed and having trouble with critical thinking. Really enjoyed my sessions and the interviewer!"

Use of the CaPPS smartphone app to boost the PST intervention was less successful, with very few participants initiating CaPPS use. The only participant who completed booster sessions in response to push notifications was

trained on the app during the second to last (rather than last) PST session, suggesting that introducing the app earlier with more time to provide support for app use could improve compliance. Additional reminders to use the app and check-ins via phone with those not properly using the app, especially early on in the study, could help promote app use, as demonstrated in a prior feasibility study on app use in chronic TBI.⁶⁶ Furthermore, other past studies using similar apps have trained participants to use the app for the first 2-4 weeks after download, closely monitoring compliance and assisting with any issues participants experienced.^{47,66-69} Overall, although app use compliance in our study was very limited, implementation of the proposed changes above may resolve many of the issues and encourage more consistent app use in future studies.

Study limitations

This was a small pilot feasibility study, and as such, we cannot make definitive conclusions about efficacy or feasibility across all settings. Though we had strong indicators of feasibility of intervention delivery, recruitment was more challenging. However, we identified multiple strategies to improve recruitment success, including translating and adapting PST for Spanish-speaking individuals, providing consumer-friendly summaries of the benefits of PST, and continuing intervention delivery after care recipient discharge. In addition to volunteer bias that can positively skew study results, we may have also had an education-related volunteer bias, because all our consenting participants had at least a high school education. Furthermore, more than half of our care partners did not live with the care recipient, suggesting that they may not be providing day to day support. Therefore, future studies should develop strategies to ensure representativeness in consenting participants and examine differences in care partner characteristics and outcomes based on whether or not they live with the care recipient after discharge. CaPPS was originally developed for adults with acquired brain injuries and their care partners, so initial development did not include the perspectives of individuals with SCI or burn injuries and their care partners. This may be one reason participant initiation of CaPPS was a problem in our study. We did identify several strategies to address this problem, and future work to find effective ways to leverage smartphone ownership to promote generalization of PST is warranted. Outside of apps, internet-based sites are increasingly smartphone optimized and emailing or text messaging links to web-based electronic boosters may be an alternative less prone to some of the barriers encountered using apps.

Conclusions

Recruiting care partners of adults with traumatic injuries and stroke into a problem-solving based self-management intervention delivered during the care recipient's inpatient rehabilitation stay is feasible for a subset of care partners, though there are several clearly identifiable barriers to maximizing participation and adherence in an early PST intervention that should be addressed. Specific strategies include continuing the intervention delivery after the care recipient's discharge and translating and adapting PST into

other languages, most notably Spanish. Delivering PST in this setting and at this time was well-accepted by care partners, very few of whom felt they had insufficient time or felt too overwhelmed to participate. This study introduces the possibility for earlier intervention and improving care partner outcomes across the transition of care from hospital to home. Furthermore, the ability of professionals with any clinical background to be trained in PST delivery enhances the potential for clinical implementation. Future studies should focus on identifying the best number of sessions and most appropriate timing of PST for care partners of adults with traumatic injuries or stroke.

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