

ORIGINAL RESEARCH

Randomized Trial of a Peer-Led, Telephone-Based Empowerment Intervention for Persons With Chronic Spinal Cord Injury Improves Health Self-Management



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Abstract

Objective: To evaluate the impact of “My Care My Call” (MCMC), a peer-led, telephone-based health self-management intervention in adults with chronic spinal cord injury (SCI).

Design: Single-blinded randomized controlled trial.

Setting: General community.

Participants: Convenience sample of adults with SCI (N = 84; mean time post-SCI, 9.9y; mean age, 46y; 73.8% men; 44% with paraplegia; 58% white).

Interventions: Trained peer health coaches applied the person-centered health self-management intervention with 42 experimental subjects over 6 months on a tapered call schedule. The 42 control subjects received usual care. Both groups received the *MCMC Resource Guide*.

Main Outcome Measures: Primary outcome—health self-management as measured by the Patient Activation Measure (PAM). Secondary outcomes—global ratings of service/resource use, health-related quality of life, and quality of primary care.

Results: Intervention participants averaged 12 calls over 6 months (averaging 21.8min each), with distinct variation. At 6 months, intervention participants reported a significantly greater change in PAM scores (6mo: estimate, 7.029; 95% confidence interval, .1018–13.956; $P = .0468$) compared with controls, with a trend toward significance at 4 months. At 6 months, intervention participants reported a significantly greater decrease in social/role activity limitations (estimate, $-.443$; $P = .0389$), greater life satisfaction (estimate, 1.0091; $P = .0522$), greater services/resources awareness (estimate, 1.678; $P = .0253$), greater overall service use (estimate, 1.069; $P = .0240$), and a greater number of services used (estimate, 1.542; $P = .0077$). Subgroups most impacted by MCMC on PAM change scores included the following: high social support, white persons, men, 1 to 6 years postinjury, and tetraplegic.

Conclusions: This trial demonstrates that the MCMC peer-led, health self-management intervention achieved a positive impact on self-management to prevent secondary conditions in adults with SCI. These results warrant a larger, multisite trial of its efficacy and cost-effectiveness.

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Persons with spinal cord injury (SCI) are at risk for many chronic and secondary health conditions that can become life-threatening if not properly managed.¹ The incidence of diabetes, heart disease,

and cancer remain high in SCI,¹ while pressure ulcers, bowel and bladder problems, pain, and depression are all common secondary conditions that affect individuals' daily functioning and quality of life.^{2,3} These health problems are often preventable and can be costly to treat.⁴⁻⁶ While prevention and early treatment are imperative, this population often does not receive appropriate care.⁷

Persons with SCI face a number of substantial obstacles to accessing quality care, including problems with transportation,^{8,9} inaccessible medical offices and equipment,⁹⁻¹¹ lack of SCI education,⁵ limited physician knowledge of SCI,^{8,12-14} and lack of access to personal care attendants.⁹ Such barriers illustrate the necessity of support resources; yet, a 2005 United Spinal Association national telephone survey found that 73% of adults with SCI could not name even 1 organization providing SCI-specific information, support, or both.¹⁵ Often, individuals with SCI must navigate the complex health care system on their own, lacking the necessary knowledge and skills to effectively manage their long-term health.^{16,17}

SCI peer support shows promise for increasing knowledge of health-related resources and encouraging self-management.^{5,18} In-person peer support can increase self-efficacy and reduce rates of secondary conditions,¹⁹ yet such support is not always affordable or feasible. Telehealth is an increasingly used, cost-effective method for providing preventive health services in SCI.^{20,21}

Professional- and peer-delivered telephone interventions have been efficacious in impacting multiple secondary conditions post-SCI, including improved management of pain and sleep problems,²¹ reduced incidence of depression,²² and increased detection of pressure ulcers.^{23,24} Telephone-based mentoring by health coaches has increased self-management behaviors,²⁵ with documented feasibility among adults with varied chronic conditions.²⁶⁻²⁸ Existing SCI peer support models primarily target individuals within 1 year postinjury, though the literature is scant.²⁹ Despite existing services and some evidence of effectiveness, community-dwelling adults with chronic SCI continue to report a host of unmet health needs.³⁰ Therefore, we developed the "My Care My Call" (MCMC) telephone intervention²⁹ targeting adults with chronic SCI, using a novel approach to peer-based counseling. Herein, we describe a randomized controlled trial to evaluate the effect of MCMC compared with usual care on participants' health self-management to prevent secondary conditions and related outcomes.

Methods

Intervention

MCMC uses the unique role of the peer health coach (PHC), who acts as a supporter, role model, and advisor.³¹ MCMC follows the health empowerment approach³² to promote skill development and facilitate motivation using consumer-centered goal-setting and coaching, education, resource referral, and support-network

building. MCMC tailors components to a participant's level of activation, as perceived by the PHC (table 1), and follows social cognitive theory³⁴ through peer modeling and support to affect health care behaviors. We previously described the intervention and feasibility pilot elsewhere.²⁹ (See supplemental appendix S1 for the protocol outline, available online only at <http://www.archives-pmr.org/>.)

Trial design

We conducted a single-blinded, randomized controlled trial of the efficacy of MCMC among community-dwelling adults living with chronic SCI. The study received necessary institutional review board approval. Two PHCs, both ≥ 5 years post-SCI, received training in basic peer mentoring skills, vulnerable populations, and brief action planning, a highly structured goal-setting conversation guide for supporting self-management behaviors following the health empowerment approach, incorporating the spirit of motivational interviewing.³⁵

On completion of the baseline assessment, the study's biostatistician used a computer-generated list of random numbers to allocate participants in a 1:1 ratio, following a stratified, fixed-block randomization design to ensure balance by the 3 recruitment sites (in Massachusetts and Connecticut).

Intervention participants received the *MCMC Resource Guide*, developed by clinical experts and piloted by consumers, containing information and local resources. Additionally, the PHC called them for 6 months with optional text or e-mail contact in between. Following other effective health coach interventions,^{25,31,36} the PHC called participants weekly for months 1 and 2, biweekly for months 3 and 4, and monthly for months 5 and 6. Participants had the option to continue at a higher frequency at each transition point. The PHCs used an online tracking system^{37,38} to document call process data.

Participants in the control group received their usual health care with no new peer or other support services, and the *MCMC Resource Guide*.

Participants

The study enrolled 84 adults (≥ 18 y) with chronic traumatic SCI (≥ 1 y postinjury) with telephone access (fig 1), who endorsed an unmet primary prevention or self-management need. Recruitment involved self-selection via advertisements through community organizations and outpatient rehabilitation clinics, recruitment calls using an internal opt-in general recruitment database, and referrals from community collaborators.

Sample size

With $N = 84$ (42 per group), we had 80% power to detect an effect size of .62 between the study groups' change scores from baseline to 6 months. Assuming 10% attrition, we achieved 80% power to detect an effect size of .66. All power calculations were based on a power of .80 and a 2-sided alpha equal to .05.

Data collection procedures

On consent, the project coordinator collected demographic information about injury, race, income level, marital status, and living circumstances from participants by phone during initial eligibility screening, and later collected additional background items at baseline phone interview.

List of abbreviations:

CDSMP	Chronic Disease Self-Management Program
cLDA	constrained longitudinal data analysis
MCMC	My Care My Call
PAM	Patient Activation Measure
PHC	peer health coach
SCI	spinal cord injury

Table 1 Description of PAM levels 1–4 and how the PHC targeted the MCMC intervention based on the PHC-perceived PAM level

PAM Level Description			
Level 1	Level 2	Level 3	Level 4
Scores 0.0–47.0	Scores 47.1–55.1	Scores 55.2–67	Scores 67.1–100.0
Individuals may lack the confidence to participate in and direct their own health. They could be passive when it comes to important health decisions or be deprived of needed care because they are unsure of how to navigate the complex health care system.*	Individuals may lack the skills and knowledge needed to take an active role in managing their health care. They can be easily discouraged by barriers and may not assert themselves when receiving care.*	Individuals may take some steps in participating but still lack the confidence and skills to fully manage their own health. These people may need to build their self-advocacy skills in order to receive needed health care.*	These individuals are effectively managing their health and health care. They are confident in their abilities to navigate health care barriers, actively seek out health information, and participate in more preventive health behaviors. Though they are willing and able to manage their health, the trials and tribulations of daily life can make these behaviors difficult for them to maintain.*
PHC Strategy by Level of Activation			
Level 1: Increasing Knowledge and Confidence	Level 2: Improving Confidence in Knowing How	Level 3: Encouraging Practice and Taking Action	Level 4: Anticipating Change and Managing Triggers
<p>PHC can help people to increase/improve:</p> <ul style="list-style-type: none"> • Belief/knowledge of being more involved in managing their health care needs • Assertiveness • Ability to problem-solve • Ability to make health-related decisions • Ability to identify a problem they need skill development in • Awareness of and ability to access resources/supports • Ability to navigate the health care system • Relationship with PCP by asking questions about treatment and care options • Ability to seek out preventive services • Ability to find and use support networks 	<p>PHC can help people to improve <i>how</i> to increase:</p> <ul style="list-style-type: none"> • Knowledge regarding the health effects of SCI • Ability to navigate the health care system • Relationship with PCP by asking questions about treatment and care options • Ability and confidence to find a PCP • Ability to find and use support networks • Assertive behaviors 	<p>PHC can help people to improve/increase:</p> <ul style="list-style-type: none"> • Ability to use services and resources available • Ability to practice and take action toward becoming more empowered with problem-solving, health decision-making, and addressing barriers • Assertiveness • Managing frustration 	<p>PHC can help people to improve ability to increase/improve:</p> <ul style="list-style-type: none"> • Coping with new or unfamiliar situations when they arise • Times of stress • Maintaining recently adopted behaviors during stressful situations • Being aware of/identifying stressors/triggers and practicing preventive and coping/recovery techniques

Abbreviations: PAM, Patient Activation Measure; PCP, primary care physician.

* Hibbard & Cunningham,³³ 2008.

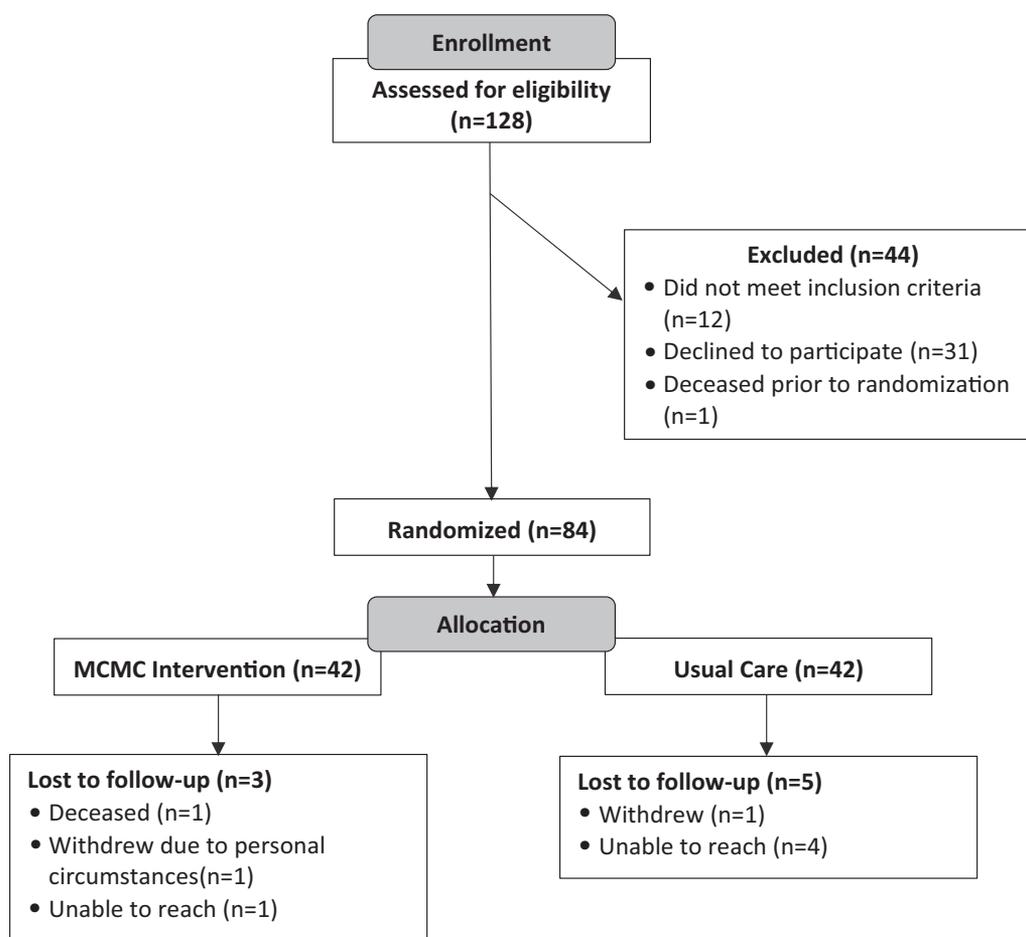


Fig 1 Participant flow.

The project coordinator administered outcome assessments via phone at baseline and 6 months. To maintain blinding of the project coordinator and any study staff handling data, an unblinded research assistant collected a small subset of primary outcome and intervention-only process data at 2- and 4-month follow-up.

Outcomes

Our primary outcome, self-management, refers to a person's ability and willingness to take on the daily management of his/her health and health care.³³ We measured self-management using the Patient Activation Measure (PAM), a 13-item scale that is well tested, with an internal consistency reliability (coefficient α) of .87 in samples with and without chronic illness.^{39,40} The PAM scale ranges from 0 (lowest) to 100 (highest), indicating the extent of a person's knowledge, skill, and confidence for self-management of his/her health and health care.^{39,41} Scores are then associated with levels 1 to 4 of activation, which indicate clinically relevant cut-point profiles to provide tailored, effective services and support (see [table 1](#)).

Secondary measures of self-management

Secondary outcomes included social/role activity limitations, global perceptions of change in resources, health-related quality of

life, communication with one's physician, and satisfaction with health care services.

Social/Role Activities Limitations is a 4-item self-report measure of limitations within the past 2 weeks on a 5-point Likert scale from "not at all" to "totally" limited,⁴² developed by the Stanford Chronic Disease Self-Management Program (CDSMP). It has an internal consistency reliability (coefficient α) of .91 and a test-retest reliability of .68.⁴²

Global Rating of Change involves 2 adapted items that assess change over time on a 10-point Likert scale⁴³ for awareness of services and resources and use of services and resources. Two follow-up questions ask how many services and resources they are aware of and have used. Similar scales have shown high test-retest reliability in patients with chronic lower back pain (intraclass correlation coefficient, .90).⁴³

For health-related quality of life, we used the SCI standard data set, a 3-item measure of satisfaction with general quality of life, physical health, and psychological health, on a scale from 0 (completely dissatisfied) to 10 (completely satisfied).⁴⁴ It has an internal consistency reliability (coefficient α) of .81 in this population.⁴⁵

The Communication With Physicians Scale is a 3-item measure of engagement in communication behaviors with health care providers on a 5-point Likert scale from "never" to "always," developed by the Stanford CDSMP. It has an internal consistency reliability (coefficient α) of .73 and a test-retest reliability of .89.⁴²

The Patient Satisfaction Scale has 10 items on a 5-point Likert scale from “strongly disagree” to “strongly agree” to measure general satisfaction with primary care physicians, displaying a reliability (coefficient α) of .98 in the general population.⁴⁶

Statistical methods

Descriptive statistics characterized the sample. We calculated the mean and SD for continuous variables, and frequency distributions for categorical variables. Because of the small sample size, we dichotomized some categorical variables (eg, race: white or nonwhite). Regarding baseline comparisons, for continuous variables we used the 2-sample Student *t* test without assumption of equal variances to test mean score differences between groups (eg, Satterthwaite approximation test for degrees of freedom); for categorical variables we used the chi-square test to compare proportional differences between study groups.

For the primary outcome, PAM overall score, we applied constrained longitudinal data analysis (cLDA)⁴⁷ to examine differences in mean change scores at each time point (2, 4, and 6mo) from baseline between groups, following intention to treat. The cLDA model uses data from all 84 subjects, in which fixed effects and interaction terms at all time points are tested in a single model. We treated both baseline and follow-up outcomes as dependent variables. Fixed effects included time, study group, and difference between study groups at each time point. Additionally, the study team (including PHCs) identified the fixed effects of age, sex, and level of injury as common factors often matched in peer relationships; and race, education, and comorbidity status as important social determinants of health and health literacy. The final fixed effect was interaction between time and each covariate. The unstructured variance-covariance matrix accounted for repeated measures within each subject. We reported the mean and 95% confidence interval for group differences in change score from baseline to each posttreatment time point.

In subgroup analysis, we applied cLDA to look at the treatment effect on difference in PAM change score at each follow-up time point in each of the following subgroups: education level (higher/lower); race (white/nonwhite); having social support or not; years postinjury (≤ 6 y/higher); injury type (tetraplegia/paraplegia); and sex.

For other secondary continuous outcomes, we applied the same model to examine treatment effects, except for the Global Rating of Change, where linear regression was used, since these 2 items were only collected at 6 months. For categorical analysis of the 4-level PAM variable, we followed a similar method, but applied generalized estimating equations to examine the treatment effect at each time point.

All analyses were conducted using Statistical Analysis System software, version 9.1.^a

Results

Participant flow

Of 128 potential participants assessed for eligibility (see fig 1), 44 were excluded at initial screen (prerandomization). In total, 84 subjects were randomized, of whom 76 (90.5%) completed the study. Two intervention group participants were lost to follow-up, and 1 withdrew; 4 control group participants were lost to follow-up, and 1 withdrew.

Sample characteristics

The sample consisted of 84 community participants with SCI who were aged 18 to 78 years (mean, 46y); 73.8% men; 44% paraplegic; 1 to 66 years postinjury (mean, 9.9y); and 58% white, 25% African American, 12% Latino, and 5% other. At baseline, participants’ average PAM score was 67.97, with 15% at PAM level 1 or 2 (lower activation), 45% at level 3, and 40% at level 4 (most activated). For social/roles activities limitations over the last 2 weeks, subjects scored on average 1.65 (1, slightly limited; 2, moderately limited). Only baseline marital status was significantly different, with fewer married/living with partner, more single, and more divorced/widowed in the intervention versus control group (tables 2 and 3).

Engagement with the intervention

On average (\pm SD), intervention participants completed 12 \pm 5 calls (minimum, 1 call; maximum, 21 calls) over 6 months, averaging 21.8 \pm 7.5 minutes each (minimum, 2min; maximum, 35min). Participation duration averaged 147 \pm 48 days (minimum, 0d; maximum, 181d). When the PHC offered call frequency reduction at each transition point, 16.7% of participants chose to follow the established call frequency schedule and reduce call frequency, while 83.3% opted to continue at the current, higher level of more frequent calls. The average call length decreased by about 1 minute every 2 months.

Table 2 Background characteristics of study sample

Characteristic	Control	Intervention	Total
Female	23.8 (10) <i>P</i> = .8044	28.6 (12)	26.2 (22)
Age (y)	47.5 \pm 14.4 <i>P</i> = .2566	44.0 \pm 13.4	45.7 \pm 14
Hispanic or Latino	11.9 (5) <i>P</i> > .99	11.9 (5)	11.9 (10)
Race			
White	64.3 (27)	52.4 (22)	58.3 (49)
African American	21.4 (9)	28.6 (12)	25 (21)
Other	14.3 (6) <i>P</i> = .5421	19.1 (8)	16.7 (14)
Marital status			
Single	42.9 (18)	59.5 (25)	51.2 (43)
Married/living with partner	38.1 (16)	14.3 (6)	26.2 (22)
Divorced/separated/widowed	19.1 (8) <i>P</i> = .0460	26.2 (11)	22.6 (19)
Education			
High school or less	59.5 (25)	57.1 (24)	58.3 (49)
\geq College	40.5 (17) <i>P</i> \geq .99	42.9 (18)	41.7 (35)
Income level			
\leq \$20,000	44.7 (17)	56.4 (22)	50.7 (39)
\leq \$50,000	23.7 (9)	20.5 (8)	22.0 (17)
$>$ \$50,000	31.6 (12) <i>P</i> = .5725	23.1 (9)	27.3 (21)
Currently employed	11.9 (5) <i>P</i> \geq .99	11.9 (5)	11.9 (10)

NOTE. Values are % (n), mean \pm SD, or as otherwise indicated.

Table 3 Clinical characteristics and baseline status of study sample

Clinical Characteristic	Control	Intervention	Total
Age at injury (y)	35.8±16.8 <i>P</i> =.7637	34.48±14.9	35.3±15.8
Years since injury	11.0±13.1 <i>P</i> =.3550	8.8±8.1	9.9±10.9
Type of injury			
Paraplegia	52.4 (22)	35.7 (15)	44.1 (37)
Tetraplegia	47.6 (20)	64.3 (27)	55.9 (47)
	<i>P</i> =.1870		
PAM score	66.9±15.6 <i>P</i> =.5024	69.1±14.1	68±14.8
PAM level			
1	9.5 (4)	2.4 (1)	6 (5)
2	9.5 (4)	9.5 (4)	9.5 (8)
3	45.2 (19)	45.2 (19)	45.2 (38)
4	35.7 (15)	42.9 (18)	39.3 (33)
	<i>P</i> =.5574		
Had comorbidity (eg, diabetes, circulatory disorders, smoking)	35.71 (15) <i>P</i> >.99	35.71 (15)	35.71 (30)
Social/role activities limitations	1.6±1.1 <i>P</i> =.7696	1.7±1.32	1.7±1.2
Quality of life	6.3±2.8 <i>P</i> =.6767	6.5±2.5	6.4±2.6
Communication With Physicians Scale	3.4±1.2 <i>P</i> =.4681	3.2±1.1	3.2±1.1

NOTE. Values are mean ± SD, % (n), or as otherwise indicated.

Change in health self-management over time

Table 4 and figure 2 summarize findings for the PAM score and corresponding level at 3 time points (2, 4, and 6mo). Intervention participants reported a significantly greater change in PAM scores at 6 months compared with the control group, with a trend toward significance at 4 months. Additionally, PAM scores achieved an estimated 1 level of improvement in activation for intervention subjects at 4 and 6 months (eg, from level 2 to 3).

We conducted exploratory subgroup analyses of results from the adjusted model to begin to discern future research. PAM change scores were higher in the intervention group for the following subgroups: high social support (ie, married or same

personal care assistant for ≥6mo) (at 6mo, *P*=.0216); 1 to 6 years postinjury (at 6mo, *P*=.0440); tetraplegia (at 4mo, *P*=.0280; at 6mo, *P*=.0145); males (at 4mo only, *P*=.0124); white (approaching significance at 4mo, *P*=.0541; at 6mo, *P*=.0557); and higher education level (at 6mo, *P*=.0116). We also explored the matching of various PHC and participant characteristics (ie, years postinjury, injury type, sex), with no significant results.

Secondary measures of self-management

Table 5 reports secondary outcomes. At 6 months, intervention participants reported a significantly greater decrease in social/role activities limitations compared with controls, as well as a greater change in life satisfaction. They also reported a greater change in services/resources awareness, a greater overall service use, and a greater number of services used. We found no significant changes for the Communication With Physicians Scale or the Patient Satisfaction Scale.

Discussion

This study demonstrates the efficacy of a novel intervention, the MCMC peer support model, on improving self-management for individuals with chronic SCI. These findings align with other recent behavioral intervention results targeting acute SCI, showing increased peer support self-efficacy scores through a peer-led inpatient education intervention,⁴⁸ as well as through a peer mentoring program,¹⁹ which also decreased medical complications.

Notably, MCMC significantly affected our primary self-management outcome of health activation through a greater change over time in both PAM scores and activation level. The intervention group's estimated increase in PAM score at 6 months from baseline was 7.029 points higher than for controls. Notably, each point increase in PAM score correlates to a 2% decrease in hospitalization and a 2% increase in medication adherence.⁴⁹

Additionally, increased activation is associated with improved health outcomes like normal high-density lipoprotein cholesterol levels, Patient Health Questionnaire-9 depression scores, and serum triglyceride levels.^{33,50} Further, positive outcomes associated with higher patient activation have led to fewer instances of costly emergency department visits and hospitalizations.^{50,51}

PAM levels of activation offer clinically relevant profiles to more effectively support each individual (see table 1). One study⁵⁰

Table 4 Difference in PAM change score and change in level between study groups from baseline to 2-, 4-, and 6-month follow-up time points*

Difference in:	2-Month Follow-Up			4-Month Follow-Up			6-Month Follow-Up		
	<i>P</i>	SE	Estimate	<i>P</i>	SE	Estimate	<i>P</i>	SE	Estimate
Change Score [†]	.2270	3.2845	4.0035	.0609	3.2351	6.1694	.0468*	3.4735	7.0286
	<i>P</i>	SE	OR	<i>P</i>	SE	OR	<i>P</i>	SE	OR
Change in Level [‡]	.0792	0.4485	2.197455	.0315*	0.6028	3.65538	.0375*	0.4662	2.637417

Abbreviation: OR, odds ratio.

* Covariates included age, sex, race, education, injury type, and comorbidity, as well as time, study group, difference between study groups at each time point, and interaction between time and each covariate.

[†] cLDA applied.

[‡] Generalized estimating equation applied.

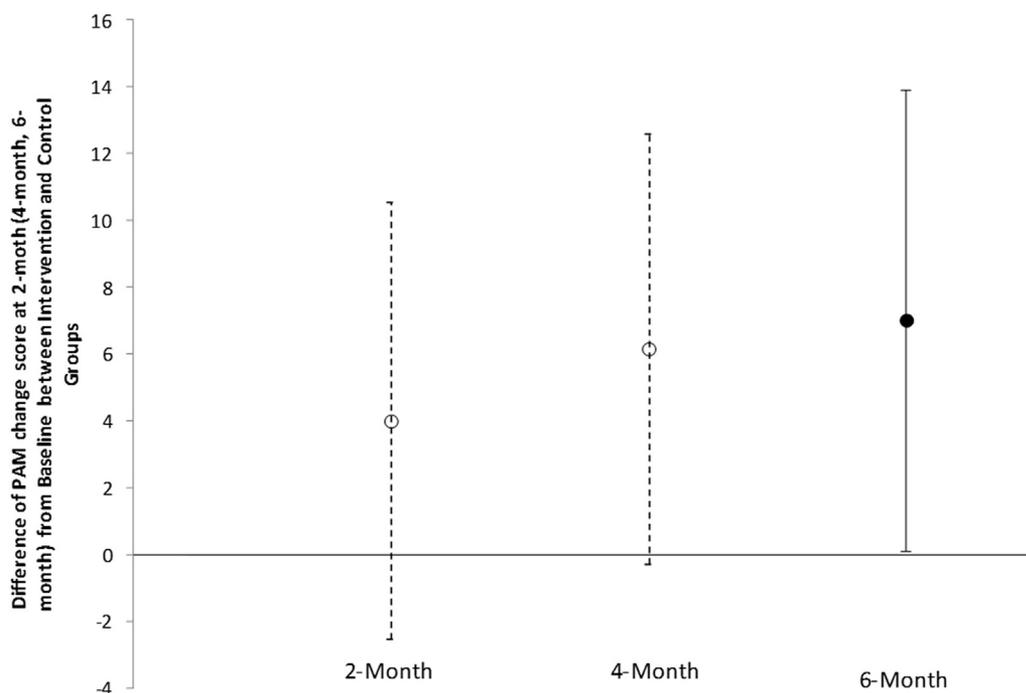


Fig 2 Mean and 95% confidence interval of score difference of treatment and control group in PAM change score from baseline to 2-month, 4-month, and 6-month time points. ○, confidence interval spans zero; ●, confidence interval does not span zero.

found that patients with activation levels 3 and 4 had projected health care costs 13% lower than at level 2, and 8% lower than at level 1. MCMC intervention participants displayed 1 entire level of significant improvement in activation at 4 months, sustained at 6 months. Although only 15% reported baseline PAM levels at 1 or 2, in exploring trends in mean change scores, we found them to be higher when stratified by baseline PAM level for the intervention group at every time point except level 4.

MCMC also improved secondary outcomes of social/role activities limitations and life satisfaction, 2 important and basic aspects of improving the lives of people with SCI. Notably, 1 study⁵² targeting community-dwelling adults with chronic SCI using peer navigators through home visits also reported increased participation. Another similar peer-led study⁵³ targeted new injuries via phone using motivational interviewing, an evidence-based therapy technique, and showed clinical improvements in depression/anxiety

and aspects of SCI coping. We know of no similar interventions to date reporting an impact on life satisfaction.

The intervention had no effect on secondary outcomes related to primary care visits. It may be that other types of interventions would be more appropriate, focused in the primary care setting or on primary care providers, rather than patients. Alternatively, a longer follow-up period may be needed to capture enough primary care interactions to detect significant differences. To this end, adapting more Stanford CDSMP elements—shown to affect these outcomes⁵⁴—may improve the MCMC PHC approach, focusing on specific elements identified by people with SCI as most important to include in a CDSMP program.⁵⁴ For example, the top 3 topics to include were (1) exercise, (2) nutrition, and (3) pain management.

After 1 year postinjury, most individuals with chronic SCI are under the care of a family physician without SCI specialty

Table 5 Secondary outcomes

Difference in change score (at 2 time points—0 and 6mo)*	Difference Between Study Groups		
	P	SE	Estimate
Social/role activities limitations	.0389	.2098	-0.4431
Quality of life	.0522	.5110	1.0091
Communication With Physicians Scale	.9897	.2495	0.0032
Patient Satisfaction Scale	.6489	.1579	0.0721
Difference in actual score (at 6mo only) [†]			
Global rating of change			
Change in service/resource awareness	.0253	.7338	1.678
Service/resource use	.0240	.4633	1.069

* cLDA applied.

[†] Generalized estimating equation applied.

training,⁵⁵ with high levels of reported unmet needs.⁵⁶ Thus, self-management becomes a critical component to preventing secondary conditions.^{5,18,57,58} Preliminary subgroup analyses of PAM scores suggest that MCMC may have been helpful to several subgroups in particular: men, for whom effective health behavior interventions require different considerations than for women⁵⁹⁻⁶¹; participants with tetraplegia, who often have greater self-care and health care needs; and those within 1 to 6 years postinjury, likely representing an active ongoing period of adjustment. As the first study of its kind focusing on chronic SCI, it is worth further exploring each of these tentative results.

The study's positive effect on global knowledge and use of resources and services for health self-management has particular clinical implications, given a real need for information and support for people with chronic SCI to address unmet health needs.^{30,56}

Further research

A larger multisite trial is needed to provide replication and enhanced generalizability of these findings, cost effectiveness, as well as exploring the best mode of implementation for scalability of the model across varied community- and rehab-based settings. Recruiting a greater number of subjects could clarify the main effects of race and education for this population on patient activation outcomes, and allow for further delineation of the efficacy of specific PHC tools and roles. A longer study period, including postintervention data collection up to 6 months, would capture any sustained change from the intervention, as well as secondary condition outcomes.

Study limitations

Given the small, pilot nature of this trial in 1 area of the country, the generalizability of results is limited. Also, as a convenience sample, individuals who responded to our request to participate are likely a priori more motivated—and possibly more activated in self-management—than their nonparticipating peers. We looked to maximize generalizability by ensuring that potential enrollees reported a need within the intervention's scope, and by fielding referrals for participation. We did not track or exclude subjects based on concurrent receipt of peer services. Our study demonstrates the overarching challenge of engaging in research individuals with SCI with lower activation levels, perhaps by virtue of this trait or because of less frequency in SCI (see Heinemann et al⁶²) and other populations.⁶³

Conclusions

This study demonstrated that a novel, telephone-based, peer-led self-management empowerment intervention using PHCs can achieve meaningful improvements in self-management for adults with chronic SCI, warranting a larger, multisite trial including secondary conditions outcomes.

Supplier

a. Statistical Analysis System software, version 9.1; SAS Institute Inc.

Keywords

Peer influence; Rehabilitation; Spinal cord injuries; Telemedicine

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Supplemental Appendix S1 Protocol: My Care My Call

Peer-Led Health Empowerment Training in Chronic Spinal Cord Injury

Site information

Primary: New England Regional Spinal Cord Injury Center, Boston University School of Public Health

Collaborators: Gaylord Hospital, Hospital for Special Care

Funding: National Institute on Disability, Independent Living, and Rehabilitation Research (grant no. 90SI5013)

ClinicalTrials.gov Identifier: NCT02878070

Principal Investigator: Alan Jette, PT, PhD

Overview

My Care My Call (MCMC) is an innovative, peer-led telephone intervention designed to empower adults with chronic spinal cord injury (SCI) in the self-management of their primary health care needs to prevent secondary conditions. In a randomized controlled trial, participants assigned to the MCMC intervention receive tapered calls from a peer health coach (PHC) for 6 months. PHCs are experienced, empathetic peer mentors living with SCI who act as supporters, role models, and advisors, providing goal-setting support, motivation, education, and resource referral to participants. Participants complete surveys at baseline, 2, 4, and 6 months, as well as qualitative exit phone interviews.

It is hypothesized that MCMC will (1) increase participants' self-management skills and behaviors, (2) improve participants' experiences in engaging in primary care, and (3) increase health-related quality of life and medical social support compared with those receiving usual care. Additional secondary hypotheses state that the MCMC intervention will increase access to primary care and increase use of preventive health services compared with those receiving usual care.

Study design

Type: Interventional

Design: Randomized controlled trial

Endpoint Classification: Efficacy study

Intervention Model: Parallel assignment

Masking: Double-blind (investigator, outcomes assessor)

Primary Purpose: Prevention of secondary health conditions

Participants recruited: 84

Eligibility	
Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Age 18 or older • Self-report of physician-confirmed traumatic SCI diagnosis • Injured 1 year ago or more • Telephone access for at least 9 months • Speaks and understands conversational English • Have a current health issue to address 	<ul style="list-style-type: none"> • Moderate to severe cognitive impairment • Surgery scheduled for a 2-week or longer duration during the months of the study

Study arms

1. Experimental: Peer Health Coaching
 - Participant receives calls from a PHC for 6 months
 - Weekly calls for 2 months, biweekly calls for 2 months, monthly calls for 2 months
 - Participant is given *My Care My Call Resource Guide*
2. No Intervention: Usual Care
 - Participant is given *My Care My Call Resource Guide*

Outcomes		
Measure	Description	Time Points
Primary: Self-Management Behavior		
Patient Activation Measure	A 13-item scale that ranges from 0 (lowest) to 100 (highest) indicating the extent of a person's knowledge, skill, and confidence for self-management in relation to his/her health and health care. Scores are then associated with levels 1–4 of activation.	Baseline, 2, 4, 6 months
Secondary: Limitations		
Social/Role Activities Limitations	A 4-item self-report measure of limitations within the past 2 weeks, using a 5-point Likert scale.	Baseline, 6 months
Secondary: Service/Resource Use		
Global Ratings of Service/Resource Use	4 items that assess change in awareness of services/resources (unchanged to much more aware) and use of services/resources (much less use to much more use) in the past 6 months.	Baseline, 6 months
Secondary: Quality of Life		
Health-Related Quality of Life	A 3-item measure asking individuals to rate their satisfaction with general quality of life, physical, and psychological health on a scale from 0 (completely dissatisfied) to 10 (completely satisfied).	Baseline, 6 months
Secondary: Quality of Primary Care		
Communication With Physicians Scale	A 3-item measure asking participants to indicate how often they engage in communication behaviors with their health care providers on a 5-point Likert scale.	Baseline, 6 months
Patient Satisfaction Scale	A 10-item scale that measures patients' general satisfaction with their primary care physicians on a 5-point Likert scale.	Baseline, 6 months