

ORIGINAL RESEARCH

Empowering Adults With Chronic Spinal Cord Injury to Prevent Secondary Conditions



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Abstract

Objective: To develop and assess the feasibility of My Care My Call, an innovative peer-led, community-based telephone intervention for individuals with chronic spinal cord injury (SCI) using peer health coaches.

Design: Qualitative pilot study.

Setting: General community.

Participants: Convenience sample of consumer advocates with traumatic SCI ≥ 1 year postinjury (N=7).

Interventions: My Care My Call applies a health empowerment approach for goal-setting support, education, and referral to empower consumers in managing their preventive health needs. For feasibility testing, peer health coaches, trained in brief action planning, called participants 6 times over 3 weeks.

Main Outcome Measures: Identified focus areas were acceptability, demand, implementation, and practicality. Participant outcome data were collected through brief after-call surveys and qualitative exit interviews. Through a custom website, peer health coaches documented call attempts, content, and feedback. Analysis applied the constant comparative method.

Results: My Care My Call was highly feasible in each focus area for participants. Concerning acceptability, participants were highly satisfied, rating peer health coaches as very good or excellent in 80% of calls; felt My Care My Call was appropriate; and would continue use. Regarding demand, participants completed 88% of scheduled calls; reported that My Care My Call fills a real need; and would recommend it. Considering implementation, peer health coaches made 119% of expected calls, with a larger focus on compiling individualized resources. For practicality, call duration averaged 29 minutes, with 1 hour of additional time for peer health coaches. Participant effects included feeling supported, greater confidence toward goals, and greater connection to resources. Subsequently, several process changes enhanced peer health coach training and support through role-plays, regular support calls, and streamlined My Care My Call support materials.

Conclusions: After process changes, a randomized controlled trial to evaluate My Care My Call is underway.

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Adults with chronic spinal cord injury (SCI) are susceptible to a host of secondary conditions associated with their injury, while also being at higher risk for chronic illnesses. Prevention and early treatment requires diligent self-management accompanied by access to primary health care services.¹ Researchers emphasize the essential role that primary care physicians play in health

maintenance and promotion for patients with SCI, especially for routine age- and sex-appropriate preventive health care.^{2,3} However, 1 survey found that 63% of people with SCI reported having a primary care need within the last 6 months, 33% of which were reportedly never met.⁴ In another study, although 93% of adults with SCI internationally (United States included) had a family doctor, only 56% also had an SCI specialist.⁵ Consequently, a large minority must rely solely on their primary care physician's capacity to address all of their health care needs.

People with SCI must navigate many environmental barriers to access health services, including attitudinal barriers,⁶⁻⁹ physical barriers,^{7,9-12} transportation issues,^{9,13} limitations in access to personal care attendants,⁹ and lack of physician knowledge.¹³⁻¹⁵ The Special Interest Group on Spinal Cord Injury Model System Innovation¹⁶ reports that people with SCI receive preventive services at lower rates than the general population, often because of the lack of accessible equipment in physicians' offices, including examination tables, scales, and preventative screening equipment (eg, mammography machines). Lack of proper primary health care puts adults with SCI at a heightened risk of a number of serious illnesses and secondary conditions that are otherwise preventable.¹⁶⁻¹⁸

However, for a complex set of reasons, many people with SCI lack essential skills to navigate these barriers to access and maintain quality primary health care.¹⁹⁻²¹ One survey found only half of people with SCI receive care coordination services¹⁵ and therefore must coordinate their own primary care. People with SCI who use social supports to help coordinate health care needs have shown improved health outcomes²² and increased self-management.²³ Concurrently, people with SCI are largely unaware of available support resources. When asked to name an organization for people with SCI, 73% of participants with SCI could not name one entity.²⁴

These disparities call for a targeted effort to increase consumer awareness of health-related resources and bolster self-management skills to prevent secondary conditions post-SCI.^{16,23} Face-to-face peer support has shown qualitatively to be an effective agent for delivering information and skills building and reducing medical complications in adults with acute SCI,²⁵⁻²⁷ whereas telephone interventions delivered by SCI professionals and/or peers have demonstrated reduced incidence of depression,²⁸ increased detection of pressure ulcers,²⁹ and improved management of pain and sleep difficulties postinjury.³⁰ Telehealth has become increasingly recognized for its potential for cost-effectiveness in the provision of health care services.^{30,31} Studies combining telephone-delivery and health-related mentoring via health coaches in other chronic illnesses have shown efficacy in improving self-management outcomes^{32,33} and demonstrated high feasibility and acceptability when targeting the adoption and maintenance of positive health behaviors.^{34,35} We know of no published evaluations of peer-led community interventions specifically targeting people with chronic SCI or focused on prevention of secondary conditions post-SCI (supplemental table S1, available online only at <http://www.archives-pmr.org/>).

My Care My Call is an innovative, community-based telephone intervention designed to support adults with chronic SCI in managing their health care needs to prevent common secondary conditions post-SCI.³⁶ We subsequently describe the My Care My Call intervention development, describe feasibility testing for

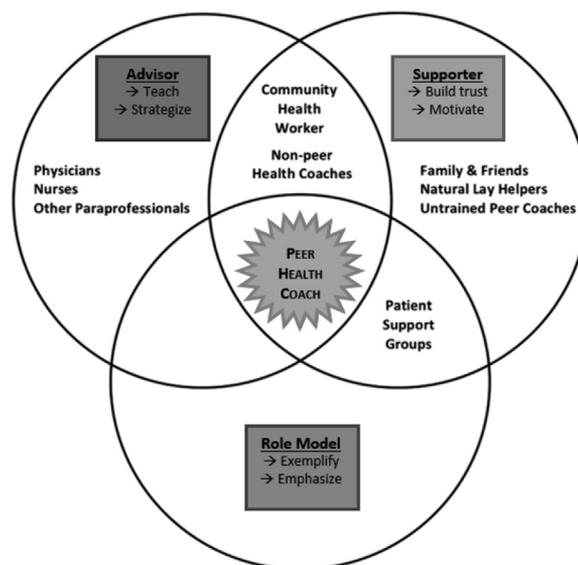


Fig 1 Peer health coach roles.

consumers, and discuss preliminary findings and future research priorities.

Methods

Development of the My Care My Call intervention

My Care My Call is designed according to a health empowerment approach,³⁷ where health coaches support participants with chronic SCI in meeting their health care needs to prevent secondary conditions. My Care My Call supports skill development and facilitates motivation using consumer-centered goal setting and coaching and resource referral and support network building. These elements encourage successful self-management of health care needs, which in turn could prevent secondary conditions and optimize overall health outcomes for the individual.^{32,33} The intervention is also influenced by the transtheoretical model³⁸ by tailoring the intervention to a participant's level of activation and social-cognitive theory³⁹ by using peer modeling and peer support to affect health care behaviors.

A group of diverse SCI professionals developed My Care My Call, co-led by an individual living with SCI for 25 years, and advised by a 5-person SCI content expert panel. Targeted outcomes included improved self-management skills and accessing necessary health care services to prevent secondary conditions and maximizing overall health-related quality of life post-SCI.

My Care My Call consists of 2 components. Component 1 consists of peer health coaches. A peer health coach is an experienced, empathetic peer mentor living with SCI (≥ 5 y postinjury). My Care My Call peer health coaches act as advisors, supporters, and role models to empower peers in managing their health care needs (fig 1).⁴⁰ Peer health coach training included basic peer mentoring skills, special considerations for vulnerable populations, and internal study intervention and protocol review. Figure 2 lists My Care My Call topics.

Peer health coaches additionally received training and certification in brief action planning. Brief action planning is a highly structured, evidence-informed tool for supporting self-

List of abbreviations:

SCI spinal cord injury

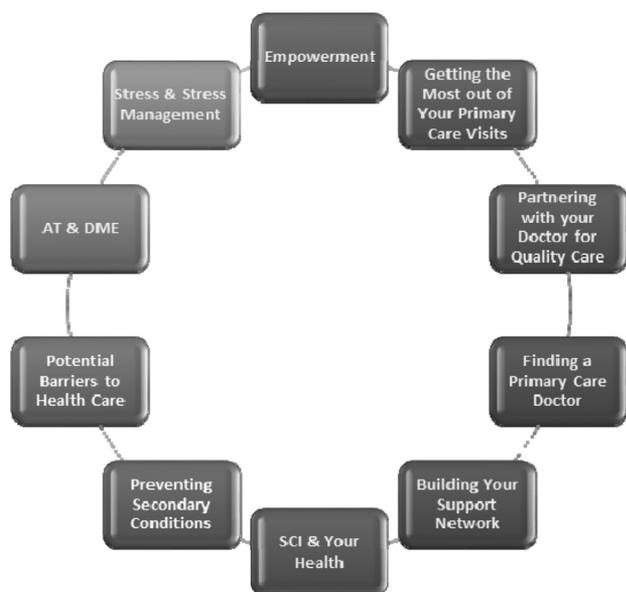


Fig 2 My Care My Call preventative health topics. Abbreviations: AT, assistive technology; DME, durable medical equipment.

management behaviors. Following the health empowerment approach, brief action planning incorporates the spirit of motivational interviewing into the guided goal-setting process/conversation. Peer health coaches also use the motivational interviewing concept of change talk to gauge a consumer's readiness to make a health-related action plan. Peer health coaches follow brief action planning to evoke consumers' specific health goals and assess level of confidence for success, while facilitating problem-solving for low confidence and assuring follow-up. Figure 3 provides a typical call flow.

My Care My Call involved 2 peer health coaches, both acting as part-time paid employees contributing to the My Care My Call intervention development from its inception. One peer health coach also acted as project coinvestigator based on her past training and experience. The second peer health coach was identified and recruited through the Connecticut-affiliated SCI peer organization.

Component 2 consists of My Care My Call support materials. Peer health coaches developed a toolkit to guide them through each call using scripted conversation outlines and flow charts. It also covered brief action planning, essential motivational interviewing skills, and peer health coach peer support options (eg, using talk back for peer education). The peer health coach consistently followed the spirit of motivational interviewing, empowering the peer in agenda setting at every turn.

The My Care My Call intervention also included a consumer workbook, which integrated existing and original information and worksheets to support consumer skill development.⁴¹⁻⁴³ The resource list identified essential, comprehensive informational and local resources.

Preliminary feasibility study methods

We conducted a small study to ascertain preliminary feasibility of the My Care My Call intervention via participant interviews and peer health coach observations (as the interventionists) for a subsequent pilot efficacy study. We addressed 4 elements of feasibility per Bowen et al⁴⁴: acceptability, demand,

implementation, and practicality. Under each feasibility area we chose related outcomes to guide quantitative and qualitative data collection and analysis.

The feasibility study's target population was adults (≥ 18 y) with chronic traumatic SCI (≥ 1 y postinjury) with telephone access. We received necessary institutional review board approvals to recruit from 3 study sites: 1 in Massachusetts and 2 in Connecticut. We generated a recruitment list of active community leaders in an advocacy role (eg, peer mentor, board member for disability advocacy organization, past advisor to other research projects) from varied backgrounds to provide critical feedback on study components. Eight individuals approached agreed to participate. We excluded 1 consented individual who dropped out prior to participating because of illness. Peer health coaches were employed investigators engaged on the study protocol acting as research agents; therefore, the institutional review boards did not require approval to report peer health coaches' feedback on improving intervention delivery. Examining the intervention's effect on peer health coaches (eg, benefits to peer health coaches) would qualify them as subjects, requiring institutional review board approval.

On enrollment, the research assistant matched 3 participants each to peer health coaches by sex and assigned 1 additional participant to our more experienced female peer health coach by locale. Peer health coaches called participants twice weekly for 3 weeks at a mutually agreeable time. After each call, participants completed a brief online survey (supplemental appendix S1, available online only at <http://www.archives-pmr.org/>), including rating the peer health coach's performance on a 5-point Likert scale, most/least helpful call elements, improvements for any support materials used, and any other feedback. The research assistant compiled responses for analysis into a standard spreadsheet software package from the online database.

On exit, the research assistant, acting as the interviewer, conducted qualitative in-depth, open-ended phone interviews of 10 to 15 minutes in duration with each participant (supplemental appendix S2, available online only at <http://www.archives-pmr.org/>) to assess each element of feasibility. We grouped exit interview questions into 3 categories: (1) overall feedback (eg, program satisfaction); (2) feedback for specific features/components (eg, peer health coach role and support materials); and (3) suggestions for improvement. The interviewer documented responses in real time on data collection forms, including direct participant quotes. The research assistant did not audio record interviews. Postinterview, each participant received a \$50 gift card.

The peer health coaches developed a custom-built online tracking system^{45,46} using web-based forms to document call content and brief action planning goal setting. Peer health coaches offered feedback in weekly team calls, documented by the study director via real-time meeting notes.

The interviewer analyzed call adherence data and ratings of peer health coach descriptively in a standard spreadsheet software package. The interviewer analyzed qualitative after-call survey and exit interview data using the constant comparative method⁴⁷ to group responses into the outcomes of interest by the feasibility focus areas previously described.⁴⁴ In analyzing exit interview responses, the interviewer used directed content analysis⁴⁸ where, based on the 3 interview guide questions, they first identified key concepts as coding categories and then coded the text with these predetermined codes based on the interviewer's analysis of meaningful qualitative elements,⁴⁹ adding new codes for any data not fitting into one of the predetermined categories. There were 5 finalized codes:

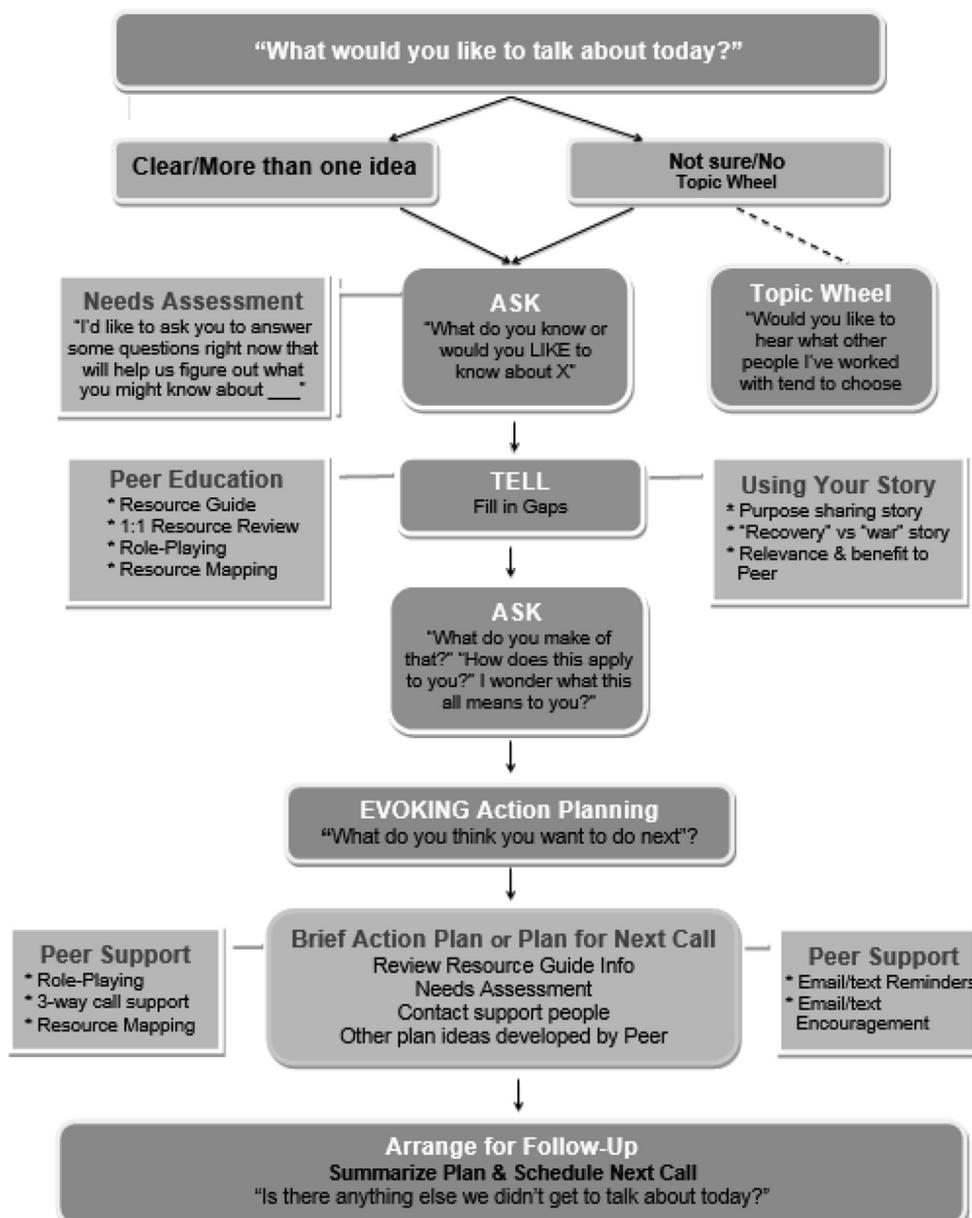


Fig 3 Structure of a typical My Care My Call.

program improvements, peer health coach improvements, suggested resources, feelings of support, and convenience of intervention (emerged). The study director reviewed and approved all finalized codes and coded interviews. The interviewer then analyzed the data for emergent themes according to selected feasibility domains (table 1).

Results

Table 2 presents the demographic background of the 7 participants. Four lived in Massachusetts, and 3 lived in Connecticut.

Feasibility results by focus area

Table 3 lists each feasibility area, related outcomes, and supporting quantitative data. For qualitative data, we subsequently

present only the most informative consumer quotes, with further quotes provided in table 3.

Acceptability

Satisfaction

Participants' comments illuminated high after-call performance ratings of peer health coaches. They expressed satisfaction with each peer health coach role listed in figure 1. Regarding the role model, "The Coach has been easy to speak with. They certainly want to help and provide information." Regarding the supporter/coach, "I like that my [personal health coach] PHC is prompting me and pushing me along to reach my goal. I probably would have dragged my feet a little bit." Regarding the mentor, "[The peer health coach] sent me links for me to get a better understanding of what we were discussing."

Table 1 Content analysis coding scheme

| Exit Interview Question Categories | Coding Categories | Feasibility Domains |
|---|-----------------------------|---|
| Overall feedback | Feelings of support | <ul style="list-style-type: none"> • Acceptability • Demand • Practicality |
| | Convenience of intervention | <ul style="list-style-type: none"> • Acceptability • Implementation • Practicality |
| Feedback for specific features/components | Suggested resources | <ul style="list-style-type: none"> • Demand • Implementation |
| Suggestions for improvement | Program improvements | <ul style="list-style-type: none"> • Acceptability • Implementation |
| | PHC improvements | <ul style="list-style-type: none"> • Acceptability • Implementation |

Abbreviation: PHC, peer health coach.

Perceived appropriateness

Consumers generally agreed that “[My Care My Call] would be helpful for someone that is not familiar...or is intimidated by the system or needs a pep talk.”

Intent to continue use

Both participants and peer health coaches expressed reluctance at the study’s end despite only 3 weeks of duration. Several participants planned to continue using the My Care My Call support materials.

Demand

Actual use

Participants demonstrated high levels of engagement, completing nearly all scheduled peer health coach calls. The My Care My Call focus on primary prevention needs appeared useful because participants discussed relevant needs outlined in [table 2](#). Usage rates indicated that participants found the resource list more useful than the workbook (in 43% vs 13% of calls, respectively).

Table 2 Pilot study sample characteristics (N=7)

| Characteristics | Value |
|----------------------|-------|
| Age, range (y) | 24–64 |
| Years injured, range | 9–27 |
| Sex | |
| Female | 3 |
| Male | 4 |
| Race/ethnicity | |
| White | 5 |
| Black | 1 |
| Hispanic | 1 |
| Level of injury | |
| Paraplegia | 2 |
| Tetraplegia | 5 |
| Complete | 4 |
| Incomplete | 3 |

NOTE. Values are counts or as otherwise indicated.

Perceived demand

Participants felt that My Care My Call would meet a real need: “This would be a great help for people with both a new SCI and...injured for a long time. There is so much information that someone with SCI can use to guide them through life and not feel overwhelmed.”

Although recruited as active consumer advocates, participants nonetheless presented with a host of sometimes urgent needs and concerns. As participants aptly expressed, “Sometimes you just need to talk to somebody and they might give you another perspective.” As well as, “...it actually gave me a sense of relief to know that I might be able to get what I’m needing.”

Expressed interest to use

Every participant would definitely recommend My Care My Call to peers, and some had already done so. One participant specifically reported the desire to participate if offered in the community.

Implementation

Degree of execution

Two indicators demonstrate that peer health coaches fully executed the intervention. First, peer health coaches made 19% more call attempts than protocol required. Second, they completed nearly all related online tracking forms documenting that they fully executed calls (see [fig 3](#)).

Success of execution

Peer health coaches successfully executed three quarters of attempted calls and completed brief action planning goal setting with all but 1 participant. Although initially lacking, peer health coaches reported building skill in offering support materials over time, confirmed by participants.

Types of resources needed to implement

The peer health coaches focused much more than anticipated on creating personal support packages. After each call, peer health coaches would select and primarily e-mail participants tailored resources from the workbook and resource list, with subsequent follow up. Although somewhat time intensive, this proved critical to participant engagement.

Factors affecting implementation ease or difficulty

Peer health coaches and participants reported that peer health coach’s use of texting and flexible call scheduling facilitated engagement. Participants and peer health coaches found it confusing and cumbersome to use the resource list separate from the workbook. Finally, peer health coaches found team calls to be vital for problem-solving and ongoing support.

Practicality

Efficiency of implementation

Both peer health coaches and participants reported call length to be reasonable. Peer health coaches estimated 1 hour of time, including preparation beforehand, documenting call content, and compiling personal support packages.

Effects on the target population

Participants highlighted 3 basic benefits. The first was increased confidence toward meeting their goals: “Evaluating my progress so

Table 3 MCMC pilot feasibility results summary

| Pilot Focus Area | Outcome of Interest | Quotes/Supporting Evidence |
|------------------|---|---|
| Acceptability | Satisfaction | <p>PHC calls:</p> <ul style="list-style-type: none"> • Participants rated their PHC either very good or excellent after 80% of calls. • PHC as role model: easy to speak with; wants to help and provide information. • PHC as supporter/coach: prompting and pushing to reach goal. • PHC as a mentor: sent links for better understanding <p>Support materials:</p> <ol style="list-style-type: none"> 1. "The Workbook and Resource List were great. They had a wealth of information." 2. "[The Resource List] highlights a lot ways for someone with SCI to have the tools [for] better care." |
| | Perceived appropriateness | <ul style="list-style-type: none"> • Helpful for people intimidated or unfamiliar with the system to provide encouragement. |
| | Intent to continue use | <ul style="list-style-type: none"> • "I will definitely hold on to [the Resource List] for future reference for guidance." |
| Demand | Actual use | <ul style="list-style-type: none"> • Participants completed 88% of scheduled calls with their PHC. • Participants reported using the resource list in 43% of calls and the workbook in 13% of calls. • Relevant topics discussed: pressure sore education; obtaining a specialized hospital bed; stress management; exercise; insurance appeals; and understanding medical marijuana. |
| | Perceived demand/need | <ul style="list-style-type: none"> • Helpful for people with new and chronic injuries. • Wealth of information for guidance to avoid feeling overwhelmed. |
| | Expressed interest to use | <ul style="list-style-type: none"> • "I would recommend this to other people and take advantage of it if it was available through a local peer organization." |
| Implementation | Degree of execution | <ul style="list-style-type: none"> • PHCs made 119% of expected calls. |
| | Success or failure of execution | <ul style="list-style-type: none"> • PHCs had a 74% success rate in completing a call with a participant. • PHCs reported completing 6 BAPs with participants. • "The PHC makes me look at things the 'smart' way; you make me figure out the things I need to do." |
| | Type of resources needed to implement | <ul style="list-style-type: none"> • PHCs focused on creating PSPs. |
| Practicality | Factors affecting implementation ease or difficulty | <ul style="list-style-type: none"> • Scheduling: "Scheduling calls with the PHC was convenient for my busy schedule." • Support materials: "I don't know the difference between the two books." • PHCs reported that team calls provided problem-solving and ongoing support. |
| | Efficiency of implementation | <ul style="list-style-type: none"> • PHC calls lasted an average of 29min, with a few notably longer calls upfront. • PHCs estimated 1h of time for call preparation, documenting call content, and compiling PSPs. |
| | Positive effects on target participants | <ul style="list-style-type: none"> • Confidence toward meeting goals. • Feeling supported. • Connection to resources. |

Abbreviations: BAP, brief action planning; MCMC, My Care My Call; PHC, peer health coach; PSP, personal support package.

far and planning a strategy to deal with the people I'm contacting. [My peer health coach] made sure I would have the proper mindset so I could get what I needed without frustration." The second was feeling supported by their peer health coach: "...I liked having someone there to talk with about everything that's going on...[these are] overwhelming topics so it was nice to have someone put that in perspective." The third was increased connection to available resources: "[Talking with the peer health coach] just gives me hope that there are resources out there for me and people like me."

Discussion

Preliminary results suggest that My Care My Call is feasible in all 4 focus areas, bolstering support for a peer coach model empowering individuals with chronic SCI through regular phone support and consumer-directed goal setting. Participant feedback confirmed literature findings that individuals with chronic SCI

have unresolved health care needs that may influence subsequent risk of secondary conditions,⁴ which leave them feeling disempowered and overwhelmed, indicating a service gap that novel interventions (eg, My Care My Call) could address.

Peer health coaches found that peer support facilitated My Care My Call's empowerment approach using the spirit of motivational interviewing, perhaps through the comparable dimensions of equitability, mutuality, and acceptance.²⁷ Clark et al⁵⁰ especially advocate building self-efficacy to empower disenfranchised individuals with SCI to improve self-management. My Care My Call participants stated being very satisfied with the peer health coach's 3 roles, reporting a range of positive effects despite only 3 weeks of participation. Many expressed unanticipated benefits, including a sense of relief to actually receive meaningful support to address their health care needs.

My Care My Call offers a feasible application of the health coach model to peer mentoring in chronic SCI, encompassing into one program the consumer-recommended strategies of

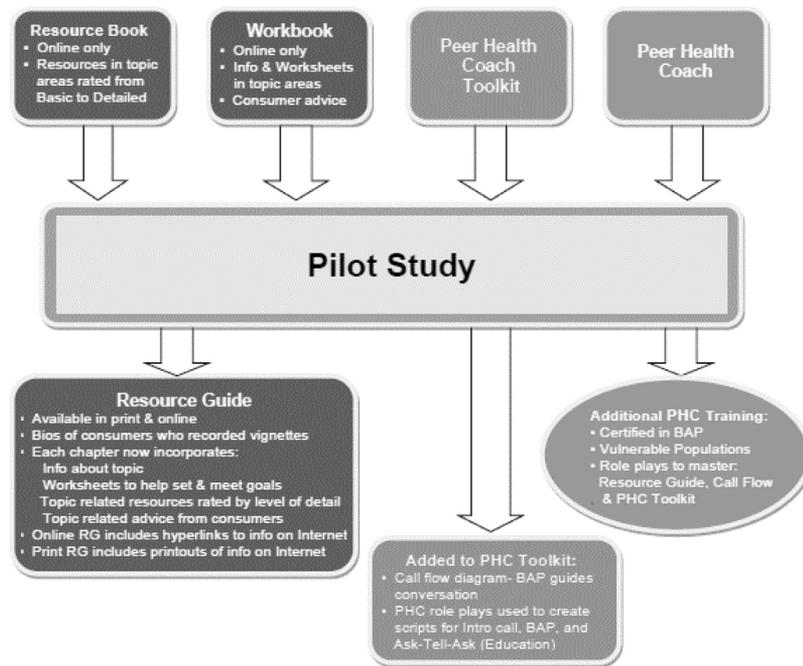


Fig 4 Chart illustrating the critical process changes. Abbreviations: BAP, brief action planning; PHC, peer health coach; RG, Resource Guide.

fostering information sharing, self-education, and assertiveness.^{33,36,51,52} Peer delivery provides social support, which correlates to better health and lower frequency of health problems,⁵³ disability-related problems, and secondary conditions.^{22,54} Notably, the peer health coach's critical role as advisor beyond the more traditional peer support roles of role model and mentor cannot be underestimated; participants with diabetes valued a similar, telephone-based self-management intervention more when delivered by a nurse advisor versus a peer because they found traditional peer support lacking in desired information and advice.³⁴ My Care My Call feasibility participants reported getting much-needed information and advice, perhaps through tailored personal support packages, a critical peer health coach follow-up tool.

Process changes

Figure 4 illustrates the critical process changes.

Enhancements to peer health coach training and support

Some feasibility participants suggested more peer health coach training to ensure naturalistic, focused conversations. Correspondingly, peer health coaches requested more practice in applying My Care My Call tools in real time. Therefore, post-testing, peer health coaches completed 19 case study role-play calls over 12 weeks with study team members, including an observer/notetaker. Concurrently, peer health coaches implemented weekly mutual support calls to share techniques and revise materials further. Overall, peer health coaches described role-plays and mutual support calls as invaluable training tools.

Revising peer health coach support materials

Peer health coaches observed that, for facilitating relation building with participants, peer support techniques superseded elements of motivational interviewing. Therefore, we replaced the

motivational interviewing tool in the peer health coach toolkit with comparable peer support skills, such as simple reflective listening statements and open-ended questions.

Peer health coaches implemented changes to minimize preparation and follow-up and improve call efficiency. They scripted more of the peer health coach toolkit to facilitate focused, participant-driven conversations and choose optimal word phrasing when transitioning among tools. Concurrently, they reworked the customized online tracking system to better align with the toolkit and streamline call documentation. They also streamlined the resource list and consumer workbook into a single comprehensive resource guide.

Future research

A pilot randomized controlled trial is underway to examine My Care My Call's short-term efficacy. If efficacious, future research could focus on sustainability by testing the feasibility of My Care My Call's practicality and integration potential⁴⁴ in a larger, multisite trial, comparing effectiveness of the My Care My Call's peer health coach model with traditional peer mentoring services, especially given initial evidence that extending the peer mentoring role in newly acquired SCIs could decrease medical complications.²⁶ Further study of key stakeholder perspectives could shed light on whether the rehabilitation facility is the most appropriate and sustainable infrastructure to incorporate the peer health coach role, as Hammel et al²⁰ advocated based on a large qualitative consumer participation study; and/or, in collaboration with a peer advocacy organization; and as a paid position or volunteer-based. Outcomes could include effect on peer health coaches in addition to peers.

Study limitations

Generalizability is clearly limited based on a small feasibility study. We specifically chose consumer advocates as participants

because of their capability to provide critical feedback for the intervention design. In turn, randomized controlled trial participants may be less activated than feasibility participants. Also, we conducted a condensed version of the intervention with feasibility participants, which precluded us from obtaining participant feedback around dosing and frequency.

Conclusions

Preliminary feasibility testing of My Care My Call yielded positive findings for acceptability, demand, implementation, and practicality. A pilot randomized controlled trial is underway to evaluate peer interactions and analyze the relation of process measures to outcomes. My Care My Call is a promising, new peer health coach model that aims to empower people with chronic SCI to develop the self-management skills, knowledge, and support needed to manage their health care needs to prevent secondary conditions.

Keywords

Community-based participatory research; Feasibility studies; Rehabilitation; Spinal Cord Injuries; Telemedicine

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Supplemental Table S1 Summary of documented SCI peer programs

| Program | Site | Description | Mode of Delivery | Focus | Target Population | Evaluation Conducted (outcomes) | Corresponding Reference |
|---|---------------------------------------|--|--|--|--|--|--|
| Peer delivered | | | | | | | |
| Peer and Family Support Program | Christopher and Dana Reeve Foundation | National peer-to-peer mentoring program designed to provide support by matching peers with peer mentors of similar age, sex, level/type of paralysis, ethnicity, veteran status and geographic location. | In-person, 1:1 peer support and mentoring | Provide emotional support and local and national information and resources. | Individuals with paralysis, their families, and caregivers | No, best practice | Christopher and Dana Reeve Foundation ⁵⁵ |
| Spinal Network Peer Support Program | United Spinal Association | Provides peer-to-peer support for individuals with SCI, friends, and family members. | In-person, group peer support | Provide emotional support and local and national information and resources. | Individuals with SCI (primarily newly injured), their families, and caregivers | No, best practice | United Spinal Association, Spinal Cord Resource Center ⁵⁶ |
| Spinal Cord Injury Education and Peer Support Program | Shepherd Center, Atlanta, GA | Provide information to individuals with SCI through peer education. | In-person, group peer support and education; facilitated by nurse educators and led by peer mentors | Provide a forum for discussion about personal care topics and sharing practical tips and concerns. | Patients with SCI | Yes, breakout session presentation of PCORI-funded RCT (engagement and peer support self-efficacy scores both improved in those that received the peer-led education intervention) | Gassaway et al ⁵⁷ |
| NRH SCI Peer Mentoring Program | NRH, Washington, DC | Provide peer-to-peer support during inpatient care and track medical complications and assist with adjusting to life after SCI on discharge. | In-person or phone contact with a peer mentor for 1 year (weekly contact for 3mo, biweekly contact for 3mo, monthly contact for 6mo) | Assist with education and community reintegration | Adults with newly acquired SCI | Yes, article published detailing quasi-experimental, noncontrolled pretest/posttest (medical complications and doctor visits all decreased significantly; self-efficacy scores improved) | Ljungberg et al ²⁶ |

(continued on next page)

Supplemental Table S1 (continued)

| Program | Site | Description | Mode of Delivery | Focus | Target Population | Evaluation Conducted (outcomes) | Corresponding Reference |
|---|--|--|---|--|---|--|-------------------------------|
| Professional delivered Pressure Ulcer Prevention Program | University of Southern California-Rancho Los Amigos National Rehabilitation Center | Determine whether self-management and the identification of personally chosen goals, motivational interviewing, and an emphasis on making long-term lifestyle changes can affect PU incidence. | Home visits and telephone contact with occupational therapists in consultation with registered nurses for 12mo | Prevention of stage III and IV PUs | Adults with traumatic SCI; injured at least 6mo | Yes, article published detailing prospective, single-blind RCT (successful implementation with an average 90% treatment adherence rate) | Clark et al ⁵⁰ |
| HABITS (Healthy Active Behavioural Intervention in SCI) | Erasmus MC University Medical Center, Rotterdam, The Netherlands | A tailored program targeting physical activity and healthy lifestyle through education and motivational interviewing in physical activity and self-management skills. | A home visit, 5 individual phone sessions, and 5 in-person group sessions with a counselor over 16wk | Increased physical activity and enhanced self-management skills | Adults with SCI for at least 10y | Yes, article published detailing the development of a multicenter RCT (results not reported) | Kooijmans et al ⁵⁸ |
| SCI Navigator | University of South Carolina, Charleston | Provide health education to individuals with SCI to mitigate barriers to health care and other community-based services through peer navigators with SCI. | Four weekly education and individualized goal setting sessions followed by less frequent scheduled contacts with a peer navigator | Reduce the occurrence of PUs UTIs and rehospitalizations and improve community participation | Individuals with SCI | Yes, conference presentation detailing pilot testing (positive effect on knowledge of PU prevention, improvement of PUs present on enrollment, and increased participation in productive and preferred community activities) | Newman et al ⁵⁹ |

(continued on next page)

Supplemental Table S1 (continued)

| Program | Site | Description | Mode of Delivery | Focus | Target Population | Evaluation Conducted (outcomes) | Corresponding Reference |
|--|---|--|---|--|--------------------------------|--|---|
| Telecounseling program | South Australian Spinal Cord Injury Service, Hampstead Rehabilitation Centre, Northfield (Dorstyn), Australia | Provide biweekly phone consultations based on motivational interviewing to improve emotional adjustment in people with newly acquired SCI. | Seven telecounseling sessions delivered by a psychologist over a 12-wk period | Improve depression and anxiety and aspects of SCI coping | Adults with newly acquired SCI | Yes, article published detailing RCT (telecounseling participants reported clinical improvements in depression and anxiety and aspects of SCI coping immediately postintervention) | Dorstyn et al ⁶⁰ |
| Study staff delivered ACP intervention | McMaster University, Hamilton and Queen's University, Kingston, ON, Canada | Understand the effects of ACP on LTPA and coping self-efficacy. | Telephone contact with study staff for 10wk | Increase moderate to heavy LTPA and coping self-efficacy | Adults with SCI | Yes, article published detailing single-blind RCT (ACP participants reported significantly greater LTPA, scheduling, and general barriers self-efficacy. Supplementing action plans with coping plans for enhancing LTPA and coping self-efficacy beliefs among individuals with SCI beginning exercise regimens was shown to be effective.) | Arbour-Nicitopoulos et al ⁶¹ |

Abbreviations: ACP, action and coping planning; LTPA, leisure-time physical activity; NRH, National Rehabilitation Hospital; PCORI, Patient-Centered Outcomes Research Institute; PU, pressure ulcer; PUPS, Pressure Ulcer Prevention; RCT, randomized controlled trial; UTI, urinary tract infection.

Supplemental Appendix S1 My Care My Call After-Call Survey

My Care My Call After-Call Survey

Thank you for participating in the My Care My Call Pilot Study. Please answer the questions below so that we can improve our study and help people with traumatic spinal cord injury (SCI) get better access to quality primary care and preventative services.

*** 1. What is your first name?**

*** 2. When did you speak with your Peer Health Coach?**

Date MM / DD / YYYY

| | | | | |
|--|---|--|---|--|
| | / | | / | |
|--|---|--|---|--|

*** 3. Please tell us how your Peer Health Coach doing. How would you rate him or her?**

Poor

Adequate

Good

Very Good

Excellent

*** 4. What did you like most about this call? What did you find the most helpful?**

*** 5. What did you like least about this call? What did you find the least helpful?**

*** 6. While speaking with your Peer Health Coach, did you use the Resource Book?**

Yes

No

Not Sure

7. If so, please let us know what you found helpful about this tool or what you thought might need improvement.

*** 8. While speaking with your Peer Health Coach, did you use the Workbook?**

Yes

No

Not Sure

9. If so, please let us know what you found helpful about this tool or what you thought might need improvement.

*** 10. We appreciate your feedback and want to make this intervention as effective as possible. Please let us know any other comments, questions, or concerns that you have. Please be sure to tell us if anything was missing from the call that should be added in the future.**

Supplemental Appendix S2 MCMC Pilot: In-Depth Interview Questions

Benefits

- What were some of the most helpful parts of MCMC? What parts did you like least?
- What did you learn from the intervention (if anything)?
- Did you like talking with the peer health coach or being able to leave a message to have the coach follow-up with you? Why?
- What parts of the intervention were effective in supporting you to work toward your own goals in getting your health care needs met (if any)?
- Was the intervention more effective with some focus areas than others and, if yes, why? (provider problems, health problems, equipment/AT problems, insurance, community resources)?
- What parts of the intervention were effective in helping you to see your doctor for a physical or mental health visit (if any)?
- Were there any problems that you had before being in the study that MCMC really helped you to take care of? Why?
- Did you like the workbook? Why?
- Did you like the resource book? Why?
- Did you like the vignettes? Why?
- Did you like being able to talk to the nurse or having the nurse call you? Why?
- Anything else you want to say about what you got out of the TLC intervention?

Features/components

- How was it for you working with the peer health coach? If the coach was not helpful to you, why? Is there a different approach or something else for the coach that you would have preferred?

- Did you like her way of talking with you? Supporting you to set goals? Suggested changes?
- Was the workbook helpful to you in working toward your goals? Why?
- Was it helpful to talk about building up your support network? Why?
- Was there anything about MCMC that was particularly helpful? Why?
- Was the conversation too long/short or just right?
- Was the spacing between conversations too long/short or just right?
- Do you feel there was any repetition? If so, was repetition helpful to you? Was it annoying?
- How was the balance of talking to the coach versus the time in between when you were working toward your goals?

Suggestions

- Are there any questions we should have asked that we did not?
- Did any questions the coach asked bother you?
- What improvements would you recommend?
- Is there something else MCMC should be covering that is really important to people with SCI?
- Would you recommend this to other wheelchair users with SCI?
- Who is this most helpful for?
- Would you do it again?
- If MCMC was available through your local or national peer organization, would you be interested in long-term follow-up support with MCMC?
- How often would you recommend MCMC call people for long-term follow-up support? (Weekly? Biweekly? Monthly?) For how long?
- Anything else you would like to say?

Abbreviations: AT, assistive technology; MCMC, My Care My Call; TLC, Telephone-Linked Computer system.