

Award Number: W81XWH-11-2-0213

TITLE: "Family Caregivers for Veterans with Spinal Cord Injury: Exploring the Stresses and Benefits"

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REPORT DATE: October 2015

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command  
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;

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# REPORT DOCUMENTATION PAGE

*Form Approved*  
OMB No. 0704-0188

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<b>1. REPORT DATE</b> October 2015		<b>2. REPORT TYPE</b> Annual		<b>3. DATES COVERED</b> 30Sep2014 - 29Sep2015	
<b>4. TITLE AND SUBTITLE</b> "Family Caregivers for Veterans with Spinal Cord Injury: Exploring the Stresses and Benefits"				<b>5a. CONTRACT NUMBER</b>	
				<b>5b. GRANT NUMBER</b> W81XWH-11-2-0213	
				<b>5c. PROGRAM ELEMENT NUMBER</b>	
<b>6. AUTHOR(S)</b> Susan Charlifue, PhD  Jennifer Coker, MPH  E-Mail: <a href="mailto:jcoker@craighospital.org">jcoker@craighospital.org</a> ; <a href="mailto:Susie@craighospital.org">Susie@craighospital.org</a>				<b>5d. PROJECT NUMBER</b>	
				<b>5e. TASK NUMBER</b>	
				<b>5f. WORK UNIT NUMBER</b>	
<b>7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)</b>  Craig Hospital 3425 S. Clarkson Street Englewood, CO 80113				<b>8. PERFORMING ORGANIZATION REPORT NUMBER</b>	
<b>9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)</b> U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				<b>10. SPONSOR/MONITOR'S ACRONYM(S)</b>	
				<b>11. SPONSOR/MONITOR'S REPORT NUMBER(S)</b>	
<b>12. DISTRIBUTION / AVAILABILITY STATEMENT</b> Approved for Public Release; Distribution Unlimited					
<b>13. SUPPLEMENTARY NOTES</b>					
<b>14. ABSTRACT</b> When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Unfortunately, there are few studies that examine the intricacies of caregiving for people with spinal cord injuries. The purpose of this study is to identify issues specific to family caregivers of veterans with spinal cord injuries and develop a relevant, culturally appropriate instrument to assess caregiver distress and/or benefit. Family caregivers of veterans from three geographically diverse sites (Richmond, Virginia, Seattle, Washington, and Denver, Colorado) are being recruited to participate in focus groups discussing caregiving issues. To date, five focus groups with a total of 34 participants were completed in Richmond and two groups in Denver with a total of 8 participants. IRB approval in Seattle is still pending but in progress. It is anticipated that IRB approval will be finalized in Seattle within the month of October 2013 and focus groups will be convened before 2014 if possible.					
<b>15. SUBJECT TERMS</b> spinal cord injury, veterans, caregivers					
<b>16. SECURITY CLASSIFICATION OF:</b>			<b>17. LIMITATION OF ABSTRACT</b>  UU	<b>18. NUMBER OF PAGES</b>  12	<b>19a. NAME OF RESPONSIBLE PERSON</b> USAMRMC
<b>a. REPORT</b> U	<b>b. ABSTRACT</b> U	<b>c. THIS PAGE</b> U			<b>19b. TELEPHONE NUMBER</b> (include area code)

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## INTRODUCTION

**Background:** Spinal cord injury (SCI) often results in physical limitations such that receiving assistance from others is critical to maintaining health and facilitating full societal integration. In the general population, almost 70% of people with SCI receive some form of assistance and support from family members. Similarly, the availability of family caregiving is crucial to most veterans with SCI, but there is little research addressing the topic, and no appropriate and available method to comprehensively assess the strengths of and burdens on family caregivers. In the years following rehabilitation, people with SCI will have an increasing need for help as they age. With advancements in quality of care and the fact that the average age of all people living with SCI is over 45 and at least one-fourth have been injured for 20 or more years, the number of people with SCI who require home-based assistance will only increase in the coming years. This is particularly relevant for the veteran population, which is reported to be older, on average, than the general population of people with SCI.

**Research Problem:** When family caregivers are unable to cope effectively with all role responsibilities, the health and well-being of the care recipient also may be jeopardized. Ultimately, the inability to continue providing care because of declining physical or emotional health may lead to institutionalization of the care recipient. While institutionalization may be considered an acceptable option for frail elderly individuals who have numerous medical and cognitive impairments, people with SCI are likely to be younger and have many years of life ahead of them, and thus may find institutionalization unacceptable. Clearly, the health and well-being of the caregiver is an essential component that helps enable the person with SCI to function as independently as possible and participate in society. A qualitative approach takes advantage of the rich information provided by those living the experience of caregiving and SCI, enabling us to learn what matters most to these caregivers and can help inform the development of an instrument that is relevant to this unique population of family caregivers to veterans with SCI. In better assessing the issues facing family caregivers, we have the potential to address their health and emotional needs and thus positively impact the function, wellness and overall quality of life for veterans who have sustained SCI during or after their years of service.

**Specific Aims:** The goal of this project is to explicate the specific issues related to caregiving in SCI and develop a relevant and culturally appropriate instrument to assess caregiver distress and/or benefit in SCI. The development of an appropriate measurement tool will help clinicians and service providers better target their interventions, with the goal of improving the support system for veterans with SCI and their family caregivers, and thereby improving long-term outcomes for those veterans with SCI.

**Study Design:** The proposed will first entail a qualitative design that will involve focus groups of family caregivers of veterans with SCI drawn from three VA study sites. At least 5 focus groups of up to 7 participants at each site will be the minimum necessary to identify the relevant issues and themes. Audiotapes of the focus groups will be transcribed verbatim and analyzed using NVivo-8 qualitative analyses software. Coding will be conducted by three researchers to identify themes that will be used to design a relevant and culturally sensitive instrument to assess caregiver distress and benefit in SCI. Results of this study will be disseminated to relevant stakeholders via presentations and publications.

By the end of this study, the field will have definitive information about the issues facing caregiving family members to veterans with SC and will have a new instrument to assess SCI caregiver distress and benefit in this unique military population.

**Impact:** The proposed study has a high degree of relevance for veterans with SCI and their family members due to the current lack of information in this area. The knowledge gained from this research will inform clinicians as they work with families early during the SCI rehabilitation process and in the years beyond, enabling them to have a more relevant means of assessing SCI caregiving issues. Without an appropriate psychometrically sound measure of caregiving, the effectiveness of new interventions to help family caregivers cannot be assessed. The proposed qualitative and quantitative methods will provide that needed SCI-specific measure. Finally, we anticipate the study ultimately will benefit veterans with SCI themselves, as it has been noted that erosion in the health and well-being of the primary caregiver may lead to the development of expensive and preventable secondary complications in the person with SCI.

**BODY**

**Objective 1 – Identify participants and conduct focus groups/interviews 1-36)**

Task	Activities	Months	Status
1a:	Schedule and conduct collaborator teleconferences and local project site team meetings.	1-36	Completed
1b:	Obtain IRB approval from each study site	1-6	Received from Richmond and Denver, still waiting on IRB approval from Seattle. Personnel changes in Seattle have delayed this process but as of September 2013 IRB approval is expected within 30 days 2013 update: Notified by Seattle that the IRB is understaffed and not approving outside projects at this time. Seattle has withdrawn from the study. <u>2014 update:</u> West Roxbury VA in Boston has agreed to come onto the study and as of this date we are still in the IRB process. A one-year no-cost extension is being requested and we anticipate being able to complete Boston focus groups in early 2015 and complete all study activities by 9-30-15. <b>2015 update: Complete</b>

1c:	Identify study subjects	6-12	Richmond – completed Denver – completed <b>2015 update: Boston - completed</b>
1d:	Mail invitations to potential participants - A letter to the individual with SCI will explain the purpose of the study and ask them to nominate one family member who provides personal assistance to them. Identified individuals will be invited to participate in a focus group to discuss his or her caregiving experiences. Participants will receive \$60.00 to thank them for their time and compensate travel	6-12	Richmond – completed Denver – completed <b>2015 update: Boston - completed</b>
1e:	Update literature review – the existing literature review used to prepare this proposal will be updated quarterly during the first year of the project to identify any new information and themes regarding caregiving	1-12	Completed
1f:	Conduct focus groups/interviews - The PI (Charlifue) will lead each focus group at all sites along with a local facilitator	7-15	Richmond – 5 groups completed Denver – 2 groups have been completed; anticipate 2 more groups to be scheduled 2013 update – no further word from Denver regarding additional groups 2014 update: The site PI and research assistant in Denver are no longer involved with the study. No further activities anticipated from Denver. <b>2015 update: Boston – 5 focus groups were completed</b>
1g:	Identify missing topics on existing caregiver instrument (CBI, described in Project Narrative)	7-15	To be completed when all focus groups convened and transcripts analyzed <b>2015 update: Complete – see section below</b>

### Objective 2 – Analyze qualitative data

Task	Activities	Months	Status
2a:	Transcribe audiotaped sessions	7-18	Richmond being done currently – 2014 update – transcription of all Richmond and both Denver groups completed <b>2015 update: All focus groups from all three sites were transcribed</b>

2b:	Export data to NVivo 8	7-18	Pending completion of transcription 2014 update – in progress <b>2015 update - complete</b>
2c:	Perform qualitative analysis - Qualitative on-going analysis of focus group and individual interviews by the PI and two Research Assistants at Craig Hospital	7-21	Pending completion of 2b 2014 update – in progress <b>2015 update – complete although this took significantly longer than anticipated.</b>
2d:	Maintain codebook to document the coding criteria for particular thematic codes and document the sequence of analysis decisions	1-21	Pending completion of 2b 2014 update – in progress <b>2015 update - complete</b>

**Objective 3: Develop a relevant and culturally sensitive instrument to assess caregiver distress and/or benefit in SCI:**

Task	Activities	Months	Status
3a:	Identify and operationalize themes/topics	7-24	
3b:	Review of questions by focus group participants questions. This will be performed by mailing a packet with the first draft of the questionnaire as well as a stamped return envelope with instructions to rate the questions on importance, relevance, and cultural applicability. Participants will receive \$20.00 to thank them for their input	21-24	Pending completion of 2b 2014 update: only those questions unique to the veteran caregiver group will need to undergo additional review by participants. <b>2015 update: additional questions identified in the veteran group have been added to the existing civilian instrument developed by this PI for a study funded by National Institute on Disability and Rehabilitation Research. None of the questions were unique to the veteran group – all had been identified in the civilian group but some were dropped in analysis of the civilian data. It is felt that additional review was not necessary as these questions underwent evaluation previously and the time constraints were such that it was felt this step could be eliminated.</b>

3c:	Refine questions and develop pilot instrument	21-24	Partially completed; additional questions to be added after all focus groups completed 2014 update – will use same questions as developed in civilian caregiver study where themes are the same as with the veteran caregivers. New questions will be limited to themes exclusive to veteran caregivers (anticipate few) <b>2015 update – complete (see attached)</b>
3d:	Cognitive testing of the proposed questions. The cognitive interviews will be administered either in person or by telephone by the Craig team. Individuals will be paid \$25.00 for their participation in the cognitive interviews	25-27	Not yet scheduled to start 2014 update: will be done after 3c completed <b>2015 update: See above – this step felt to be redundant</b>
3e:	Revise questions based on cognitive testing and finalize first draft	25-27	Not yet scheduled to start 2014 update: will be done after 3d completed <b>2015 update: _ NA – see above</b>

#### Objective 4: Conduct pilot test of newly developed instrument

Task	Activities	Months	Status
4a:	Pilot test instrument. Participants will be asked to review and sign a newly approved consent form (submitted by each site to their respective IRB), complete the questionnaire and return it to the site Co-Investigator (then forwarded to the PI) in a provided stamped return envelope. A \$7.00 check will be included in the mailing as a “thank you” to participants	25-30	Not yet scheduled to start 2014 update: Will be done in 2015 after Boston focus groups and all analysis completed and new questions incorporated. <b>2015 update: Instrument has been sent to Boston VA for pilot testing. Awaiting their IRB approval and then will need HRPO approval before starting pilot.</b>
4b:	Enter and clean pilot test data - Data from the pilot testing will be entered into a Microsoft Access® database and checked for accuracy using a 10% quality control sample. Any discrepancies noted in the 10% sample will necessitate full double entry of all data to ensure full accuracy	27-30	Not yet scheduled to start 2014 update: To follow above <b>2015 update: As above</b>
4c:	Analyze pilot test data	30-33	Not yet scheduled to start 2014 update: To follow above <b>2015 update: As above</b>



4d:	Prepare final caregiver assessment instrument. Based on the analysis in 4c above, a final draft of a SCI caregiver assessment instrument will be prepared for a validation study in a future project	34-36	Not yet scheduled to start 2014 update: To follow above <b>2015 update: As above</b>
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**Objective 5: Dissemination**

5a:	Prepare manuscript of qualitative findings	27-36	Not yet scheduled to start 2014 update: Will be prepared before 9-30-15 <b>2015 update: Will be prepared before 9-30-16</b>
5b:	Presentations at professional meetings	18-24 and 30-36	2013 update: Presentation at State of the Science conference on Families of Injured, Ill and Wounded Veterans, September 2013 2014 update: Anticipate presentation in 2015 at DoD sponsored conference <b>2015 update: Will submit to 2016 DoD sponsored conference</b>

**ADDITIONAL INFORMATION:** The VA sites required that the PI (Charlifue) have a WOC in order to conduct the focus groups on site. Acquisition of the WOC took approximately 10 months to obtain and focus groups had to be postponed until the WOC was in hand.

UPDATE Sept 2013: due to delays in IRB approvals (and in some cases, inability to obtain IRB approval) a contingency plan to move forward with data from the 7 existing focus groups was discussed with project officer.

UPDATE Sept 2014: Boston required a new WOC pertinent to their site. This process (bringing Boston on board) has been in process since March of 2014. Anticipate all paperwork and contract with Boston to be completed by end of October 2014, IRB submission in Boston in November of 2014. Contract with Boston cannot be signed until no-cost extension approved.

**UPDATE Sept 2015 (Jan 2016): Due to delays in securing a replacement site, a one-year no-cost extension has been requested. We are currently awaiting approval of the extension.**

**KEY RESEARCH ACCOMPLISHMENTS**

No key research accomplishments to report as of yet other than the objectives achieved as noted above.

UPDATE Sept 2014 – 7 focus groups completed (5 in Richmond, 2 in Denver). 41 participants; mean age 59 years, 95% female; 51% Caucasian; 78% spouse; mean years of caregiving 11.8 (range <1-52); mean hours per day caregiving 9.9. Themes appear similar to those identified in a study of civilian caregivers with some positives noted, outweighed by negatives. Positive themes include change in self-awareness, closeness of family, increased compassion, feeling appreciated, still having family member with them. Negatives include lack of time for self, physical and emotional exhaustion, lack of spontaneity, lack of

understanding from others, lack of appreciation from family members, unexpected illnesses, dissatisfaction with hired carers and agencies, strain on family relationships. Caregivers also report changes in work (ability to maintain jobs or need to reduce hours), finances, limited travel and leisure, lack of privacy, loss of friendships.

**UPDATE Sept 2015 (Jan 2016): 12 focus groups completed – 7 as above plus 5 at West Roxbury VA near Boston. Total from all sites 59 participants; mean age 60 years; 97% female; 64% Caucasian; 73% spouse; mean years of caregiving 12.6 (range <1-52); mean hours per day caregiving 9.6. Themes as above. Topic saturation achieved.**

#### **REPORTABLE OUTCOMES**

**UPDATE Sept 2015 (Jan 2016): Instrument has been developed. Will need additional analysis based on input from participants at the West Roxbury VA. Anticipate analysis summer of 2016 with final instrument available by end of grant period September 2016.**

#### **CONCLUSIONS**

No conclusions to report as of yet.

#### **REFERENCES**

None

#### **APPENDICES**

None.

## Craig Caregiver Assessment of Rewards and Effort (C<sup>2</sup>ARE)

Please indicate how frequently the following statements are true for you at this time, as a caregiver of a family member with a spinal cord injury (SCI).

	Very Often	Some-times	Rarely	Never
1. I'm not getting enough sleep				
2. I feel completely overwhelmed as a caregiver				
3. I am able to successfully make my own needs known to my care receiver				
4. There are family members I can talk to when I have important decisions to make				
5. I feel like I don't have a minute's break from my caregiving chores				
6. I feel that others don't understand the difficulties involved with being a caregiver				
7. Having an intimate relationship is difficult				
8. I have financial concerns as a result of my need to be a caregiver				
9. I get as much exercise as I want to				
10. I feel emotionally drained due to caring for my family member with SCI				
11. Being a caregiver makes me feel useful				
12. I feel resentful toward other relatives who could but do not help				
13. I have as much freedom as I want				
14. I feel I'm the only one who can take care of my family member the right way				
15. I feel I have friends who I can count on to help me				
16. I think caregiving is a 24/7 job				
17. I am able to travel as much as I want to				
18. I feel torn between my duties as a caregiver and other responsibilities				
19. I have physical pain because of caregiving				
20. I feel trapped due to being a caregiver				
21. I am comfortable saying "no" to my family member with SCI when I need to				
22. I don't do things I want to do because of caregiving responsibilities				
23. I take good care of my own health issues				
24. My family member with SCI makes me feel useful and appreciated				
25. I feel I have lost who I am due to caregiving				
26. I have fears that I can't provide the right care for my family member with SCI				

	Very Often	Some-times	Rarely	Never
27. I feel I am more physically fit due to being a caregiver				
28. I feel depressed because of my caregiving responsibilities				
29. I can problem-solve issues that develop related to caregiving				
30. I find it hard to ask for help from others				
31. I have no spare time to do things that I want to do because of caregiving				
32. I take good care of my own health issues				
33. I don't do the things I want to because of caregiving responsibilities				
34. I feel I have to be constantly aware of what my family member with SCI wants and needs				
35. I feel my relationship with my family member with SCI has changed in a positive way				
36. I neglect my own health issues because of caregiving responsibilities				
37. My faith helps me get through each day as a caregiver				
38. I believe that I am able to have the career I want				
39. I feel I am more likely to have an injury because of caregiving duties				
40. I have someone I can talk to about my concerns/frustrations related to caregiving				
41. I feel I have no control over my life				
42. I feel stressed because of being a caregiver				
43. Having good health benefits for my loved one with SCI is a relief				
44. Caregiving takes time away from other family members and their needs				
45. I get frustrated by my care receiver's demands				
46. I can count on other family members to help out with caregiving				
47. I feel guilty when I take time for myself				
48. I make sure I have personal time for myself				
49. I feel alone with no one to turn to				
50. I feel angry because I have to be a caregiver				
51. I feel resentful toward other relatives who could but do not help				