AD______________

AWARD NUMBER: W81XWH-15-1-0278

TITLE: Spinal Cord Injury Veterans: Disability Benefits, Outcomes, and Healthcare Utilization Patterns

PRINCIPAL INVESTIGATOR: Denise Fyffe, PhD

RECIPIENT: Kessler Foundation

REPORT DATE: October 2019

TYPE OF REPORT: Final

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

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

REPORT DOCUMENTATION PAGE		*Form Approved* *OMB No. 0704-0188*

1. REPORT DATE *(DD-MM-YYYY)* Oct 2019	**2. REPORT TYPE** Final		**3. DATES COVERED** *(From - To)* 07/30/2015 - 07/29/2019
4. TITLE AND SUBTITLE Spinal Cord Injury Veterans: Disability			**5a. CONTRACT NUMBER**
Benefits, Outcomes, and Healthcare Utilization Patterns			**5b. GRANT NUMBER** W81XWH-15-1-0278
			5c. PROGRAM ELEMENT NUMBER
6. AUTHOR(S) Denise Fyffe, PhD			**5d. PROJECT NUMBER**
			5e. TASK NUMBER
			5f. WORK UNIT NUMBER
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)			**8. PERFORMING ORGANIZATION REPORT**
Kessler Foundation Inc. 120 Eagle Rock Avenue, Suite 100 East Hanover, NJ 07936			
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)			**10. SPONSOR/MONITOR'S ACRONYM(S)**
Fort Detrick - CDMRP			
U.S. Army Medical			
And Materiel Command			**11. SPONSOR/MONITOR'S REPORT**
Fort Detrick, Maryland			**NUMBER(S)**
21702-5012			
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited			
13. SUPPLEMENTARY NOTES			

14. ABSTRACT

The primary aim of the study is to use qualitative research methods to compare the impact of having additional financial resources provided to service-connected SCI Veterans with non-service connected SCI-Veterans who do not have these additional financial resources at VA and non-VA SCI Centers.

During final year of the project, the research team worked with the Community Advisory Board (CAB) to complete administrative tasks required to implement study procedures, data collection and review findings. Administrative tasks, included maintenance of IRB approval for continuation and amendment across both sites (Kessler and VANJHCS) as well as HRPO approval.

A summary of study recruitment and data collection accomplishments are described below.

Phase I: A total of 32 participants were recruited and enrolled for Phase I of the study (n=15 VANJHCS; 17 Kessler). Recruitment and enrollment was completed during year 2. Among the participants recruited 22 (68.7%) are non-service connected and 10 (31.3%) are service connected. Procurement of medical records is completed at both study sites.

Phase II: Semi-structured interviews of 30 Veterans at both sites are completed.

Phase III and IV: A total of 20 family caregivers (n=10 per site) and 20 SCI clinicians (n=10 per site) were enrolled and participated in either a focus group or interview.

Phase V: follow-up focus groups are completed. In preparation of manuscripts, data cleaning, analyses and triangulation of data across Phases 1-4 are ongoing.

15. SUBJECT TERMS

SCI Veterans, socioeconomic factors, VA disability compensation and benefits

16. SECURITY CLASSIFICATION OF: **U**			**17. LIMITATION OF ABSTRACT**	**18. NUMBER OF PAGES**	**19a. NAME OF RESPONSIBLE PERSON** USAMRMC
a. REPORT U	**b. ABSTRACT** U	**c. THIS PAGE** U	UU		**19b. TELEPHONE NUMBER** *(include area code)*

Standard Form 298 (Rev. 8-98)
Prescribed by ANSI Std. Z39.18

TABLE OF CONTENTS

1. **INTRODUCTION:** Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.

   Spinal cord injury (SCI) is among the most devastating and disabling medical conditions affecting wounded members of the military. The Department of Veteran Affairs (VA) is the single largest SCI comprehensive healthcare provider in the nation. There are approximately 42,000 Veterans with SCI eligible to receive care at the VA healthcare facilities. VA disability benefits policy is designed to provide financial compensation for disabilities sustained or re-aggravated during military service; this is called a “service connected” disability Since the cost of living with an SCI can be insurmountable, the monthly financial compensation provided to service-connected SCI Veterans can assist with access to supportive resources (e.g., assistive devices, personal aide) to help them sustain their functional independence, participate in their home life, employment, and social activities that might otherwise be inaccessible and maintain positive quality of life (QOL) Despite VA’s efforts to reduce the financial burden associated with successful rehabilitation, independent living, and community integration through disability benefits, a portion of SCI Veterans have non-service connected disabilities because their disabilities were not incurred or aggravated by their military service. Based on our literature review there are no studies to date that have compared the impact of having additional financial resources provided to service-connected SCI Veterans with non-service connected SCI-Veterans who do not have these additional financial resources. This is a notable oversight because the views and experiences of the service-connected and non-service SCI Veterans may be an invaluable source of insight to the VA Disability Compensation program’s effectiveness. Using a community-based participatory design, the proposed study intends to address this gap by using qualitative research methods compare the impact having a service-connected SCI to non-service connected SCI based on their: 1) health status; 2) functional outcomes; 3) quality of life; 4) family and household; and 4) choice of rehabilitation or medical facilities (i.e., VA Center or non-VA Center). Study findings will be used to generate a set of practice recommendations to the clinical guidelines, family interventions, caregiver training, and patient education programs that can be tested in future large-scale multi-site quantitative study to devise targeted community-based interventions.

2. **KEYWORDS:** Provide a brief list of keywords (limit to 20 words).

   SCI Veterans, socioeconomic factors, VA disability compensation and benefits

3. **ACCOMPLISHMENTS:** The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction.

   What were the major goals of the project?
   List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project, identify these dates and show actual completion dates or the percentage of completion.

   Specific Aims of the Project:
   1. Describe SCI Veterans’ reasons for seeking service-connected versus non-service connected disability compensation and the factors that influence their choice;

2. Explore the impact of service-connected and non-service connected disability benefits on: a) health status; b) functional outcomes; c) quality of life; and d) medical decisions (e.g., choice of VA SCI Center versus private sector).

3. Explore the impact of service-connection disability benefits on the SCI Veterans family caregivers and households.

4. Explore SCI clinicians' perspectives of the impact of service-connected and non-service connected SCI Veterans on the provision of adequate long-term healthcare and rehabilitation.

5. To develop a set of practice and policy recommendations about the impact of service-connected and non-service connected SCI Veterans to clinical and policy guidelines, family interventions, caregiver training and patient education programs.

SOW: Important Milestones and Percentage of Completion

	Timeline	Research Sites	% Completed
Major Task 1: Preparing to launch study	Months		
Subtask 1: Prepare IRB submission and research protocol			
Research team and CAB study kick-off and planning meeting	1-3	KF/ VANJHCS	100%
Submit for WOC clearance status at EOVA	1-3	KF/ VANJHCS	100%
Refine eligibility criteria, exclusion criteria, screening protocol	1-3	KF/ VANJHCS	100%
Finalize consent form & human subjects protocol	1-3	KF/ VANJHCS	100%
Coordinate with Sites for Kessler IRB protocol submission	1-3	KF/ VANJHCS	100%
Coordinate with Sites for Military 2nd level IRB review (ORP/HRPO)	1-6	KF/ VANJHCS	100%
Submit amendments, adverse events and protocol deviations as needed	As needed	KF/ VANJHCS	100%
Coordinate with Sites for annual IRB report for continuing review	Annually	KF/ VANJHCS	100%
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	KF/ VANJHCS	100%
Coordinate with research staff training	As needed	KF/ VANJHCS	100%
Milestone Achieved: Research staff trained	As needed	KF/ VANJHCS	100%
Major Task 2: Complete semi-structured interviews with service-connected and non-service connected SCI Veterans			
Subtask 1: Refine conduct chart review abstraction form	8-14	KF/ VANJHCS	100%
Meet with CAB to review content of chart abstraction form	12-14	KF/ VANJHCS	100%
QSR Consultation: Data collection planning (chart review) collection process, data formatting, analysis plan	12-14	KF/ VANJHCS	100%
Milestone Achieved: chart abstraction form developed	12-14	KF/ VANJHCS	100%
Milestone Achieved: 1st chart reviewed	12-14	KF/ VANJHCS	100%
Milestone Achieved: Phase I of study completed (15 charts reviewed per site)	13-16	KF/ VANJHCS	100%
Subtask 2: Refine semi-structured interview questions based on chart review results	14-18	KF/ VANJHCS	100%
Meet with CAB to review content of semi-structured interview	15-18	KF/ VANJHCS	100%
QSR Consultation: Data collection and transcription planning (interview) collection process, data formatting, analysis plan	22-24	KF/ VANJHCS	100%
Milestone Achieved: semi-structured interview questions developed	22-24	KF/ VANJHCS	100%

Milestone Achieved: 1st participant consented, screened and enrolled	22-24	KF/ VANJHCS	100%
Milestone Achieved: Semi-structured interviews with SCI Veterans begin	22-24	KF/ VANJHCS	100%
Begin subject recruitment *(Recruitment goal: n=30 SCI Veterans per study site)*	22-24	KF/ VANJHCS	100%
Monthly progress reports to CAB	3-30	KF/ VANJHCS	100%
QSR Consultation: Coding (chart review and interviews) planning and review, including inter-coder consistency	24-28	KF/ VANJHCS	80%
Milestone Achieved: Phase II of study completed	22-26	KF/ VANJHCS	80%
Major Task 3: Family Caregiver and SCI Clinician Focus Groups (Phase III & IV)			
Subtask 1: Develop and refine content of family caregiver interviews/focus groups based on SCI Veterans responses in Phase II	24-27	KF/ VANJHCS	100%
Develop content of the family caregiver interviews/focus groups and SCI clinician focus groups	24-27	KF/ VANJHCS	100%
QSR Consultation: Data collection and transcription planning (caregiver focus groups)	24-27	KF/ VANJHCS	100%
QSR Consultation: Data collection and transcription planning (clinician focus groups)	24-27	KF/ VANJHCS	100%
Milestone Achieved: Content of family caregiver interviews/focus groups & SCI clinicians completed	24-27	KF/ VANJHCS	100%
Subtask 2: Conduct Family Caregiver Interviews/Focus Groups and SCI clinician focus groups	24-27	KF/ VANJHCS	100%
Screen potential family caregivers *(N=20; 10 caregivers per site)* and SCI clinicians *(N=20; 10 clinicians per site)* and consent	24-27	KF/ VANJHCS	100%
Conduct family caregiver interviews/focus group & SCI clinician focus groups	24-27	KF/ VANJHCS	100%
QSR Consultation: Coding (caregiver and clinician focus groups) planning and periodic review, including inter-coder consistency	27-30	KF/ VANJHCS	80%
Milestone Achieved: Report findings from family caregiver interviews/focus groups and SCI clinician focus groups	27-30	KF/ VANJHCS	80%

What was accomplished under these goals?

For this reporting period describe: 1) major activities; 2) specific objectives; 3) significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative); and/or 4) other achievements. Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.

Major Task 1: Preparing to launch study		
	Timeline (months)	Significant Results or Key Outcomes
Subtask 1: Prepare IRB submission and research protocol		
Research team and CAB study kick-off and planning meeting	1-3	Complete. Veteran Disability Rating Screening Form was developed for data collection in subsequent phases of the study
Submit for WOC clearance status at EOVA	1-3	Complete
Refine eligibility criteria, exclusion criteria, screening protocol	1-3	Complete
Finalize consent form & human subjects protocol	1-3	Complete
Submit amendments, adverse events and protocol deviations as needed	As needed	Complete
Coordinate with Sites for annual IRB report for continuing review	Annually	Complete
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	Complete
Coordinate research staff training	As needed	Complete
Milestone Achieved: Research staff trained	As needed	Complete
Major Task 2: Complete semi-structured interviews with service-connected and non-service connected SCI Veterans		
AIM 1: Describe SCI Veterans' reasons for seeking service-connected versus non-service connected disability compensation and the factors that influence their choice		
	Timeline (months)	Significant Results or Key Outcomes
Subtask 1: Refine conduct chart review abstraction form	8-14	Complete
Meet with CAB to review content of chart abstraction form	12-14	Complete
QSR Consultation: Data collection planning (chart review) collection process, data formatting, analysis plan	12-14	Complete
Milestone Achieved: chart abstraction form developed	12-14	Complete
Milestone Achieved: 1st chart reviewed	12-14	Complete
Milestone Achieved: Phase I of study completed (15 charts reviewed per site)	13-16	We completed recruitment of participants for Phase I of the study: - 17 participants enrolled at Kessler - 15 participants enrolled at VANJHCS - Of the 32 participants enrolled in Phase I of the study, 22 (68.7%) are non-service connected; 10 (31.3%) are service-connected); documented multiple reasons for SCI Veterans not accessing VA benefits and compensation - Questionnaires entered into REDCap - Procurement of medical records is complete - Data entry of chart review data is complete
Subtask 2: Refine semi-structured interview questions based on chart review results	14-18	Complete
Meet with CAB to review content of semi-structured interview	15-18	- Conducted mock semi-structure interview with CAB members and Veteran volunteers - Integrated revisions into the interview script

		- Revisions were reviewed with CAB and approved by CAB members - Complete
QSR Consultation: Data collection and transcription planning (interview) collection process, data formatting, analysis plan	22-24	Complete
Milestone Achieved: semi-structured interview questions developed	22-24	Complete
Milestone Achieved: 1st participant consented, screened and enrolled	22-24	Complete
Milestone Achieved: Semi-structured interviews with SCI Veterans begin	22-24	Complete
Begin subject recruitment *(Recruitment goal: 30 service connected and 30 non-service connected)*		Complete
Monthly progress reports to CAB	3-30	Complete
QSR Consultation: Coding (chart review and interviews) planning and review, including inter-coder consistency	24-28	Ongoing
Milestone Achieved: Phase II of study completed	22-26	Complete
Major Task 3: Family Caregiver Focus Groups (Phase III)		
Subtask 1: Develop and refine content of family caregiver interviews/focus groups		
Develop content of the family caregiver interviews/focus groups and SCI clinician focus groups	24-27	Complete; scripts to guide discussions were developed, pre-tested, and IRB approved at both sites.
QSR Consultation: Data collection and transcription planning (caregiver focus groups)	24-27	Complete
QSR Consultation: Data collection and transcription planning (clinician focus groups)	24-27	Complete
Milestone Achieved: Content of family caregiver interviews/focus groups & SCI clinicians completed	24-27	Complete
Subtask 2: Conduct Family Caregiver Interviews/Focus Groups and SCI clinician focus groups		
Screen potential family caregivers *(N=20; 10 caregivers per site)* and SCI clinicians *(N=20; 10 clinicians per site)* and consent	24-27	Complete (N=20 caregivers [n=10 at each site], N=20 clinicians [n=10 at each site]).
Conduct family caregiver interviews/focus group & SCI clinician focus groups	24-27	Complete VANJHCS: 1 caregiver focus group was completed (n=9), caregiver interview was completed (n=1), and 1 clinician focus group was completed (n=10) KF: 1 caregiver focus group was complete (n=3), caregiver interviews were completed (n=7), and 1 clinician focus group was completed (n=10).
QSR Consultation: Coding (caregiver and clinician focus groups) planning and periodic review, including inter-coder consistency	27-30	Ongoing
Milestone Achieved: Report findings from family caregiver interviews/focus groups and SCI clinician focus groups	27-30	Ongoing

Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the *methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.*

Stated goals not met: Publications are ongoing deliverables that are in preparation.

What opportunities for training and professional development has the project provided?
If the project was not intended to provide training and professional development opportunities or there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe opportunities for training and professional development provided to anyone who worked on the project or anyone who was involved in the activities supported by the project. "Training" activities are those in which individuals with advanced professional skills and experience assist others in attaining greater proficiency. Training activities may include, for example, courses or one-on-one work with a mentor. "Professional development" activities result in increased knowledge or skill in one's area of expertise and may include workshops, conferences, seminars, study groups, and individual study. Include participation in conferences, workshops, and seminars not listed under major activities.

Training and Professional Development Activities		
	Training activities	Trainer(s)
1. Staff Training (Wynn/Ebanks/ Jalil)	Departmental training of SCI department and research Study specific training – manual of procedures Enrollment and recruitment Data quality IRB procedures	Denise Fyffe, PhD Ashleigh Quinn
2. RedCap	- Using REDCap: Data management in studies linking primary and secondary data at both sites (http://www.hsrd.research.va.gov/for_researchers/cyber_seminars/archives/video_archive.cfm?SessionID=1044)	- HSR&D Cyberseminar
3. Qualitative Research Methods	- Research team provided with training about qualitative methods	Denise Fyffe, PhD Kristi Jackson, PhD Faculty of the Annual Qualitative Research Summer Intensive
4. NVivo	- Planning data collection, management and integration across the phases of the study	Kristi Jackson, PhD (QUERI – Qualitative Research & Training)
5. Kessler	- Introduce the research team to the different types of medical record systems (e.g., AllScripts and TherapySource) - Kessler research team developed standardized methods to request, blind, and abstract medical records	Denise Fyffe, PhD Kessler Medical Chart Office staff (Denise D'Urso, Clinic Manager) (Lucretia Boyce, HIM Manager and Caesar Maldonado, Medical Records) Jayne Donovan, MD
6. VANJHCS	- VA medical record systems and the content of these medical records Computerized Patient Record System (CPRS) - Kessler and VANJHCS research team developed standardized methods to request, blind and abstraction of medical records - IT – use of VA study laptop - Clinical Visit Telehealth (CVT) - Continuing Education – informed consent (videos) - Chart Review using eHOST/National eHR	Carol Gibson-Gill, MD Joyce Williams, LCSW Donna Geppner, MSOL, CTTS, CIP Program Analyst/IRB Administrator (VANJHCS IRB Office) Jazmin Torres, RN BSN, SCI Telehealth Nurse Care Coodinator VANJHCS Research Office HSR&D Cyberseminars

How were the results disseminated to communities of interest?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

1. Fyffe D, Gibson-Gill C, Williams J, Quinn A. (2017). Exploring Disability Compensation Among Veterans with Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, Volume 98, Issue 12, Page e152.

2. The broadcast for Kessler Foundation's event, "Rebuilding Futures for Our Nations Heroes," was aired. Dr. Denise Fyffe's interview, in which she discussed her current spinal cord research and how it relates to veteran care aired on One-on-One with Steve Adubato on Monday, August 6 at 7pm and 11:30pm on NJTV and 12:30am on Thirteen/WNET (https://www.youtube.com/watch?v=76n3nNRmsv8).

3. Fyffe D, Williams J, Gibson-Gill C. (2018). Best of Both Worlds: Establishing fruitful partnerships between VA SCI Centers and SCI Model Systems Centers. A poster presentation at the Paralyzed Veterans of America (PVA) 8th Annual Healthcare Summit, Dallas, TX.

4. Fyffe D, Williams J, Gibson-Gill C. (2019). Best of Both Worlds: Establishing fruitful partnerships between VA SCI Centers and SCI Model Systems Centers. A Grand Rounds presentation for the Northern New Jersey Spinal Cord Injury System (NNJSCIS) at Kessler in West Orange, NJ.

What do you plan to do during the next reporting period to accomplish the goals?

If this is the final report, state "Nothing to Report."

Describe briefly what you plan to do during the next reporting period to accomplish the goals and objectives.

FINAL REPORT: "Nothing to Report."

4. **IMPACT:** Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:

What was the impact on the development of the principal discipline(s) of the project?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how findings, results, techniques that were developed or extended, or other products from the project made an impact or are likely to make an impact on the base of knowledge, theory, and research in the principal disciplinary field(s) of the project. Summarize using language that an intelligent lay audience can understand (Scientific American style).

The collaborative nature of the interdisciplinary study team, including the Community Advisory Board (CAB), researchers and clinicians, has provided us with the opportunity to educate SCI Veterans about VA benefits and healthcare as well as improve access to care.

Based on feedback from the CAB and several participants who mentioned being interested in learning more about VA benefits during their participation in the study, the research team decided to:

1. Educate all participants and from Phase I and II by mailing them the following information along with their thank-you letter:

    - 2 booklets published by the US Department of Veterans Affairs to ensure that you are informed about the benefits offered by VA: a) Federal Benefits for Veterans, Dependents and Survivors (2016 Edition); and b) Health Care Benefits Overview (2016 Edition, Volume 3)

2. Facilitate increasing participants' knowledge and access to the VANJHCS with contact information of the Spinal Cord Injury/Disorders Coordinator at the VA New Jersey Health Care System, Joyce Williams, LCSW, at 973-676-1000 x1-1729.

What was the impact on other disciplines?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how the findings, results, or techniques that were developed or improved, or other products from the project made an impact or are likely to make an impact on other disciplines.

The research team presented the study findings were presented at the SCIMS - Northern New Jersey Spinal Cord Injury System (NNJSCIS) based at Kessler in West Orange, NJ on 10/24/19.

Fyffe D, Williams J, Gibson-Gill C. (2019). Best of Both Worlds: Establishing fruitful partnerships between VA SCI Centers and SCI Model Systems Centers. A Grand Rounds presentation for the Northern New Jersey Spinal Cord Injury System (NNJSCIS) at Kessler in West Orange, NJ.

The primary goal of grand rounds was to present recommendations based on study findings to facilitate coordination of care for Veterans living with an SCI across healthcare settings (i.e., Kessler and VANJHCS):

1. Increased communication between Kessler CMO and VANJHCS SCI Chief (Co-I: Dr. Gill) with their care managers (Kessler) and SCI Coordinator (VANJHCS) about screening to patients about their veteran status. Kessler recently adopted eCW which includes "Veteran status" being identified during intake which helps the SCI inpatient team coordinate discharge planning with VANJHCS.

2. Increased SCI clinician's knowledge about the benefits of access to dual care services for SCI Veterans at both VANJHCS and Kessler.

3. Increased VANJHCS SCI clinical staff understanding about the average short length of stay at civilian hospitals and increased need of the VANJHCS SCI team responsiveness to discharge timelines across institutions after discharge.

4. Private-sector referral to VA SCI Center flyer (see Appendix 5)

5. Kessler Foundation Blog: https://kesslerfoundation.org/media/blogs

6. Kessler Foundation Facebook post of Grand Rounds: https://www.facebook.com/100001900893547/posts/3155589571181042?sfns=mo

What was the impact on technology transfer?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe ways in which the project made an impact, or is likely to make an impact, on commercial technology or public use, including:

- *transfer of results to entities in government or industry;*
- *instances where the research has led to the initiation of a start-up company; or*
- *adoption of new practices.*

Nothing to report

What was the impact on society beyond science and technology?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how results from the project made an impact, or are likely to make an impact, beyond the bounds of science, engineering, and the academic world on areas such as:

- *improving public knowledge, attitudes, skills, and abilities;*
- *changing behavior, practices, decision making, policies (including regulatory policies), or social actions; or*
- *improving social, economic, civic, or environmental conditions.*

Based on feedback from the CAB and several participants who mentioned being interested in learning more about VA benefits during their participation in the study, the research team decided to:

1. Educate all participants and from Phase I and II by mailing them the following information along with their thank-you letter:

   - 2 booklets published by the US Department of Veterans Affairs to ensure that you are informed about the benefits offered by VA: a) Federal Benefits for Veterans, Dependents and Survivors (2016 Edition); and b) Health Care Benefits Overview (2016 Edition, Volume 3)

2. Facilitate increasing participants' knowledge and access to the VANJHCS with contact information of the Spinal Cord Injury/Disorders Coordinator at the VA New Jersey Health Care System, Joyce Williams, LCSW, at 973-676-1000 x1-1729.

3. Fyffe D, Williams J, Gibson-Gill C. (2019). Best of Both Worlds: Establishing fruitful partnerships between VA SCI Centers and SCI Model Systems Centers. A Grand Rounds presentation for the Northern New Jersey Spinal Cord Injury System (NNJSCIS) at Kessler in West Orange, NJ.

4. Private-sector referral to VA SCI Center flyer (see Appendix 5)

5. Kessler Foundation Blog: https://kesslerfoundation.org/media/blogs

6. Kessler Foundation Facebook post of Grand Rounds:
https://www.facebook.com/100001900893547/posts/3155589571181042?sfns=mo

This summarizes the invaluable ways in which knowledge translation of research and consumer involvement can improve the well-being of SCI Veterans – one Veteran at a time.

5. **CHANGES/PROBLEMS:** The PD/PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction. If not previously reported in writing, provide the following additional information or state, "Nothing to Report," if applicable:

Changes in approach and reasons for change:
Describe any changes in approach during the reporting period and reasons for these changes. Remember that significant changes in objectives and scope require prior approval of the agency.

"Nothing to Report,"

Actual or anticipated problems or delays and actions or plans to resolve them
Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

"Nothing to Report,"

Changes that had a significant impact on expenditures
Describe changes during the reporting period that may have had a significant impact on expenditures, for example, delays in hiring staff or favorable developments that enable meeting objectives at less cost than anticipated.

"Nothing to Report"

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents
Describe significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period. If required, were these changes approved by the applicable institution

committee (or equivalent) and reported to the agency? Also specify the applicable Institutional Review Board/Institutional Animal Care and Use Committee approval dates.

"Nothing to Report,"

Significant changes in use or care of human subjects

"Nothing to Report,"

Significant changes in use or care of vertebrate animals

Not applicable (no research with vertebrate animals is being done)

Significant changes in use of biohazards and/or select agents

Not applicable (no use of biohazards or select agents)

6. **PRODUCTS:** List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state "Nothing to Report."

- **Publications, conference papers, and presentations**
  Report only the major publication(s) resulting from the work under this award.

  Journal publications. *List peer-reviewed articles or papers appearing in scientific, technical, or professional journals. Identify for each publication: Author(s); title; journal; volume: year; page numbers; status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

Fyffe DC, Williams J, Tobin P, Gibson-Gill C. (2019). Spinal Cord Injury Veterans: Disability Benefits, Outcomes and Healthcare Utilization Patterns: Protocol for a Qualitative Study. JMIR Research Protocols. https://doi.org/10.2196/preprints.14039

Fyffe D, Gibson-Gill C, Williams J, Quinn A. (2017). Exploring Disability Compensation Among Veterans with Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, Volume 98, Issue 12, Page e152.

Books or other non-periodical, one-time publications. *Report any book, monograph, dissertation, abstract, or the like published as or in a separate publication, rather than a periodical or series. Include any significant publication in the proceedings of a one-time conference or in the report of a one-time study, commission, or the like. Identify for each one-time publication: author(s); title; editor; title of collection, if applicable; bibliographic information; year; type of publication (e.g., book, thesis or dissertation); status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

None to date

Other publications, conference papers and presentations. *Identify any other publications, conference papers and/or presentations not reported above. Specify the status of the publication as noted above. List presentations made during the last year (international, national, local societies, military meetings, etc.). Use an asterisk (*) if presentation produced a manuscript.*

VANJHCS Research Week poster presentation; the poster is attached in Appendix 5

- **Website(s) or other Internet site(s)**
  List the URL for any Internet site(s) that disseminates the results of the research activities. A short description of each site should be provided. It is not necessary to include the publications already specified above in this section.

1. The broadcast for Kessler Foundation's veterans event, "Rebuilding Futures for Our Nations Heroes," was aired. Dr. Denise Fyffe's interview, in which she discussed her current spinal cord research and how it relates to veteran care aired on One-on-One with Steve Adubato on Monday, August 6 at 7pm and 11:30pm on NJTV and 12:30am on Thirteen/WNET (https://www.youtube.com/watch?v=76n3nNRmsv8).

2. Kessler Foundation Blog: https://kesslerfoundation.org/media/blogs

3. Kessler Foundation Facebook post of Grand Rounds: https://www.facebook.com/100001900893547/posts/3155589571181042?sfns=mo

- **Technologies or techniques**
  Identify technologies or techniques that resulted from the research activities. Describe the technologies or techniques were shared.

None to date

- **Inventions, patent applications, and/or licenses**
  Identify inventions, patent applications with date, and/or licenses that have resulted from the research. Submission of this information as part of an interim research performance progress report is not a substitute for any other invention reporting required under the terms and conditions of an award.

None to date

- **Other Products**
  Identify any other reportable outcomes that were developed under this project. Reportable outcomes are defined as a research result that is or relates to a product, scientific advance, or research tool that makes a meaningful contribution toward the

understanding, prevention, diagnosis, prognosis, treatment and /or rehabilitation of a disease, injury or condition, or to improve the quality of life. Examples include:

- *data or databases;*
- *physical collections;*
- *audio or video products;*
- *software;*
- *models;*
- *educational aids or curricula;*
- *instruments or equipment;*
- *research material (e.g., Germplasm; cell lines, DNA probes, animal models);*
- *clinical interventions;*
- *new business creation; and*
- *other.*

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Provide the following information for: (1) PDs/PIs; and (2) each person who has worked at least one person month per year on the project during the reporting period, regardless of the source of compensation (a person month equals approximately 160 hours of effort). If information is unchanged from a previous submission, provide the name only and indicate "no change".

Example:

Name:	*Mary Smith*
Project Role:	*Graduate Student*
Researcher Identifier (e.g. ORCID ID):	*1234567*
Nearest person month worked:	*5*
Contribution to Project:	*Ms. Smith has performed work in the area of combined error-control and constrained coding.*
Funding Support:	*The Ford Foundation (Complete only if the funding support is provided from other than this award.)*

Name:	Denise Fyffe, PhD
Project Role:	Principal Investigator
Nearest person month worked:	3.6 (calendar year) person months
Contribution to Project	Dr. Fyffe oversees all aspects of the research project, ensures tasks are conducted on-time and within budget, and coordinates regular study meetings to monitor the overall study progress across all sites. She led staff training in data collection and management using REDCap and NVivo software. Dr. Fyffe has ongoing

	correspondence with the all members of the CAB and research teams at both sites. Dr. Fyffe leads weekly and collaborative research team meetings as well as CAB meetings. She submitted IRB applications at KF and VANJHCS, and the update of those applications to the HRPO. Dr. Fyffe has gained WOC status at VANJHCS, and is continuing training with VA's IT. She led the development of the Disability Rating Compensation Form and Demographic questionnaires for use in Phases I and II. She has also consulted with Dr. Jackson concerning how to best use the qualitative data analysis software QSR NVivo for all phases of the study, and initiated the processes necessary to purchase a laptop for data collection at the VANJHCS. She also leads training for the research team, including initial training for Armani Wynn

Name:	Ashleigh Quinn
Project Role:	Research Coordinator (KF)
Nearest person month worked:	12 (Calendar Year) person months
Contribution to Project	Ms. Quinn coordinates the study at KF. She participated in staff training, weekly and collaborative research team meetings, as well as CAB meetings. She facilitates correspondence with the all members of the CAB and research teams at both sites. She assisted with the submissions of IRB applications at KF and VANJHCS, and the updated applications to the HRPO. Ms. Quinn obtained WOC status with VANJHCS and completed all necessary privacy and information security training requirements for the VANJHCS. She assisted in obtaining medical records for review with the patient and medical records staff, and is responsible for developing the chart abstraction protocol. Ms. Quinn has participated in numerous trainings for REDCap and NVivo 11, as well as assisted in the development of study questionnaires, scripts and procedural logistics. She assisted training research assistants.

Name:	Armani Wynn
Project Role:	Research Assistant (KF)
Nearest person month worked:	6 (calendar year) person months
Contribution to Project	On July 5, 2017 Ms. Wynn initiated her employment at the Kessler Foundation. She participates in staff training, weekly and collaborative research team as well as CAB meetings. She completed SCI departmental and study specific training requirements, including REDCAP. She has assisted with the set-up of REDCap in preparation for data input and analysis, and also helped with the development of the SCI Veteran Caregiver questionnaires.
Name:	Ruksana Jalil
Project Role:	Research Assistant (KF)
Nearest person month worked:	6 (calendar year) person months

Contribution to Project	On July 16, 2018 Ms. Jalil initiated her employment at Kessler Foundation. She is participating in staff training, weekly and collaborative research team. She is completing SCI departmental and study specific training requirements, including REDCAP. She has assisted with the set-up of REDCap in preparation for data input and analysis. She will be trained in STATA to assist with quantitative data analyses.

Name:	Carol Gill, MD
Project Role:	Co-Investigator/Collaborating Site Lead Investigator
Nearest person month worked:	1.2 (CY) person months
Contribution to Project	Dr. Gill oversees all aspects of the project taking place at the East Orange Campus of the VANJHCS. Dr. Gill participated in monthly collaborative KF team research and CAB meetings address study management, procedures, and logistics across sites. She contributed to preparation of the IRB applications and HRPO submissions. Dr. Gill also facilitated correspondence with the VANJHCS Office of Research & Development, submitted the IRB application at VANJHCS site, and assisted with any VANJHCS site contact that is necessary, including IT for the purchase of the laptop. She has assisted in trainings for the KF staff in the use of CPRS.

Name:	Joyce Williams, LCSW
Project Role:	Co-Investigator
Nearest person month worked:	2.4 (CY) person months
Contribution to Project	Ms. Williams assists Dr. Gill with all aspects of the study at VANJHCS. Ms. Williams participated in monthly collaborative KF team research and CAB meetings address study management, procedures, and logistics across sites. She contributed to preparation of both KF's and VANJHCS's IRB applications, facilitated correspondence with the VANJHCS Office of Research & Development, and assisted with the submissions to the HPRO. She has assisted in trainings for KF staff in the use of CPRS, and assists KF staff as necessary when working at the VANJHCS.

Name:	Yasheca Ebanks
Project Role:	Research Coordinator
Nearest person month worked:	1.2 (CY) person months
Contribution to Project	Ms. Ebanks started on 10/02/17 at the VANJHCS SCI Clinical Research Department. She assists with recruitment, data collection and management at the VANJHCS.

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

If the active support has changed for the PD/PI(s) or senior/key personnel, then describe what the change has been. Changes may occur, for example, if a previously active grant has closed and/or if a previously pending grant is now active. Annotate this information so it is clear what has changed from the previous submission. Submission of other support information is not necessary for pending changes or for changes in the level of effort for active support reported previously. The awarding agency may require prior written approval if a change in active other support significantly impacts the effort on the project that is the subject of the project report.

Completion of the tasks required for the final year was challenged by numerous staffing issues:

1. *Ashleigh Quinn, the study coordinator, was on family leave from March 7, 2019 for 14 weeks.*
2. *Rukshana Jalil, research assistant, completed her tenure at Kessler Foundation on May 24, 2019.*
3. *Armani Wynn, research assistant, completed her tenure at Kessler on July 31, 2019.*

No other FTE changes will be implemented for other key personnel.

What other organizations were involved as partners?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe partner organizations – academic institutions, other nonprofits, industrial or commercial firms, state or local governments, schools or school systems, or other organizations (foreign or domestic) – that were involved with the project. Partner organizations may have provided financial or in-kind support, supplied facilities or equipment, collaborated in the research, exchanged personnel, or otherwise contributed.

Provide the following information for each partnership:
Organization Name:
Location of Organization: (if foreign location list country)
Partner's contribution to the project (identify one or more)

- *Financial support;*
- *In-kind support (e.g., partner makes software, computers, equipment, etc., available to project staff);*
- *Facilities (e.g., project staff use the partner's facilities for project activities);*
- *Collaboration (e.g., partner's staff work with project staff on the project);*
- *Personnel exchanges (e.g., project staff and/or partner's staff use each other's facilities, work at each other's site); and*
- *Other*

Organization Name:	East Orange Campus of the VA New Jersey Health Care System
Location of Organization:	385 Tremont Avenue East Orange, NJ 07018

Partner's Contribution to Project:	Collaboration, facilities, and Personnel exchanges

Organization Name:	QUERI Qualitative Research and Training Kristi Jackson, PhD (President)
Location of Organization:	801 Pennsylvania #205 Denver, CO 80203
Partner's Contribution to Project:	Consultant in qualitative management and analysis in NVivo, project structure, coding and analysis plan

Organization Name:	TranscribeMe! Inc.
Location of Organization:	PO Box 2907 San Francisco, CA 94126
Partner's Contribution to Project:	Transcription Service – Kessler Foundation site only

Organization Name:	Keystrokes
Location of Organization:	1119 Colorado Ave., Suite 104, Santa Monica, CA 90401
Partner's Contribution to Project:	Transcription Service – VANJHCS vendor

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS: For collaborative awards, independent reports are required from BOTH the Initiating Principal Investigator (PI) and the Collaborating/Partnering PI. A duplicative report is acceptable; however, tasks shall be clearly marked with the responsible PI and research site. A report shall be submitted to **https://ers.amedd.army.mil** for each unique award.

QUAD CHARTS: If applicable, the Quad Chart (available on https://www.usamraa.army.mil) should be updated and submitted with attachments.

9. **APPENDICES:** Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc.
    a. Appendix 1: Updated SOW
    b. Appendix 2: Quad Chart
    c. Appendix 3: JMIR Publication
    d. Appendix 4: Grand Rounds slide presentation
    e. Appendix 5: Private-sector referral to VA SCI Center flyer

Award No: W81XWH-15-1-0278
Spinal Cord Injury Veterans: Disability Benefits, Outcomes, and Healthcare Utilization Patterns

STATEMENT OF WORK – 09/30/2015
PROPOSED START DATE September 30, 2015

Site 1: Kessler Foundation
1199 Pleasant Valley Way
West Orange, NJ 07052

PI: Denise Fyffe, PhD (DF)

Site 2: Veterans Administration New Jersey Healthcare System (VANJHCS)
East Orange Campus
385 Tremont Avenue
East Orange, NJ 07018
PI: Carol Gill, MD (CG)

Abbreviations: EOVA= East Orange Campus of the Veterans Administration New Jersey Healthcare System; KF (Kessler Foundation); CAB = Community Advisory Board

Specific Aims:

1. Describe SCI Veterans' reasons for seeking service-connected versus non-service connected disability compensation and the factors that influence their choice.
2. Explore the impact of service-connected and non-service connected disability benefits on: a) health status; b) functional outcomes; c) quality of life; and d) medical decisions (e.g., choice of VA SCI Center versus private sector).
3. Explore the impact of service-connection disability benefits on the SCI Veterans family caregivers and households.
4. Explore SCI clinicians' perspectives of the impact of service-connected and non-service connected SCI Veterans on the provision of adequate long-term healthcare and rehabilitation.
5. To develop a set of practice and policy recommendations about the impact of service-connected and non-service connected SCI Veterans to clinical and policy guidelines, family interventions, caregiver training and patient education programs.

Major Task 1: Preparing to launch study			
		Research Sites	
	Timeline (months)	**KF**	**EOVA**
Subtask 1: Prepare IRB submission and research protocol			
Research team and CAB study kick-off and planning meeting	1-3	Complete	
Submit for WOC clearance status at EOVA	1-3	Complete	
Refine eligibility criteria, exclusion criteria, screening protocol	1-3	Complete	
Finalize consent form & human subjects protocol	1-3	Complete	
Coordinate with Sites for Kessler IRB protocol submission	1-3	Complete	
Coordinate with Sites for Military 2nd level IRB review (ORP/HRPO)	1-6	Complete	
Submit amendments, adverse events and protocol deviations as needed	As Needed	Complete	
Coordinate with Sites for annual IRB report for continuing review	Annually	Complete	
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	Complete	
Coordinate with research staff training	8-11	Complete	
Milestone Achieved: Research staff trained	8-12	Complete	
Major Task 2: Complete semi-structured interviews with service-connected and non-service connected SCI Veterans			
		Research Sites	
	Timeline (months)	**KF**	**EOVA**
AIM 1: Describe SCI Veterans' reasons for seeking service-connected versus non-service connected disability compensation and the factors that influence their choice			
Subtask 1: Refine conduct chart review abstraction form	8-14	Complete	
Meet with CAB to review content of chart abstraction form	12-14	Complete	
QSR Consultation: Data collection planning (chart review) collection process, data formatting, analysis plan	12-14	Complete	
Milestone Achieved: chart abstraction form developed	12-14	Complete	
Milestone Achieved: 1st chart reviewed	12-14	Complete	
Milestone Achieved: Phase I of study completed (15 charts reviewed per site)	26-33	Complete	

Subtask 2: Refine semi-structured interview questions based on chart review results	14-18	Complete	
Meet with CAB to review content of semi-structured interview	15-18	Complete	
QSR Consultation: Data collection and transcription planning (interview) collection process, data formatting, analysis plan	22-48	Ongoing	
Milestone Achieved: semi-structured interview questions developed	22-24	Complete	
Milestone Achieved: 1st participant consented, screened and enrolled	22-24	Complete	
Milestone Achieved: Semi-structured interviews with SCI Veterans begin	22-24	Complete	
Begin subject recruitment *(Recruitment goal: 30 service connected and 30 non-service connected)*	22-24	Complete	
Monthly progress reports to CAB	3-48	Complete	
QSR Consultation: Coding (chart review and interviews) planning and review, including inter-coder consistency	24-48	Ongoing	
Milestone Achieved: Phase II of study completed	26-48	Ongoing	
Major Task 3: Family Caregiver and SCI Clinician Focus Groups (Phase III & IV)			
		Research Sites	
	Timeline (months)	**KF**	**EOVA**
Subtask 1: Develop and refine content of family caregiver interviews/focus groups based on SCI Veterans responses in Phase II	24-27	Complete	
Develop content of the family caregiver interviews/focus groups and SCI clinician focus groups	24-27	Complete	
QSR Consultation: Data collection and transcription planning (caregiver focus groups)	28-33	Complete	
QSR Consultation: Data collection and transcription planning (clinician focus groups)	24-28	Complete	
Milestone Achieved: Content of family caregiver interviews/focus groups & SCI clinicians completed	24-28	Complete	
Subtask 2: Conduct Family Caregiver Interviews/Focus Groups and SCI clinician focus groups			
Screen potential family caregivers *(N=20; 10 caregivers per site)* and SCI clinicians *(N=20; 10 clinicians per site)* and consent	24-33	Complete	

Conduct family caregiver interviews/focus group & SCI clinician focus groups	24-33	Complete	
QSR Consultation: Coding (caregiver and clinician focus groups) planning and periodic review, including inter-coder consistency	27-48	Ongoing	
Milestone Achieved: Report findings from family caregiver interviews/focus groups and SCI clinician focus groups	27-48	Ongoing	
Major Task 4: Qualitative Data Analysis & Dissemination			
		Research Sites	
	Timeline (months)	**KF**	**EOVA**
QSR Consultation: Data collection and transcription planning (evaluation focus groups)	37-48	Complete	
Conduct qualitative data analyses (triangulate qualitative data)	37-48	Ongoing	
Develop practices and policy recommendations with CAB	24-48	Complete	
Conduct evaluation focus groups *(N=20; 10 participants per site)*	40-44	Complete	
QSR Consultation: Coding (evaluation focus groups) planning and periodic review, including inter-coder consistency	40-44	Complete	
QSR Consultation: Review of coding, triangulation of data sources, strategies for identifying other key patterns and findings for dissemination efforts	37-48	Ongoing	
Work with research team and CAB to disseminate findings at national professional meetings (e.g., abstracts, presentation, publications)	37-48	Ongoing	
Milestone Achieved: Practice & Policy Recommendations Reports generated from study findings	37-48	Ongoing	

	Yr 1	**Yr 2**	**Yr 3**	**EWOF**
Q1			Chart Review: 15 charts reviewed per site In-depth interviews: 30 service connected and 30 non-service connected veterans Caregiver focus groups: 10 caregivers (per site) (n=20)	In-depth interviews: 30 service connected and 30 non-service connected veterans *Evaluation focus groups (N=20; 10 participants per site)*
Q2		Chart Review: 15 charts reviewed per site In-depth interviews: 30 service connected and 30 non-service connected veterans Caregiver focus groups: 10 caregivers (per site) (n=20) SCI clinician focus groups: 10 SCI clinicians (per site) (n=20)		
Q3	Chart Review: 15 charts reviewed per site			
Q4				

Spinal Cord Injury Veterans: Disability Benefits, Outcomes, and Healthcare Utilization Patterns

Log #: SC140270 Award #W81XWH-15-1-0278

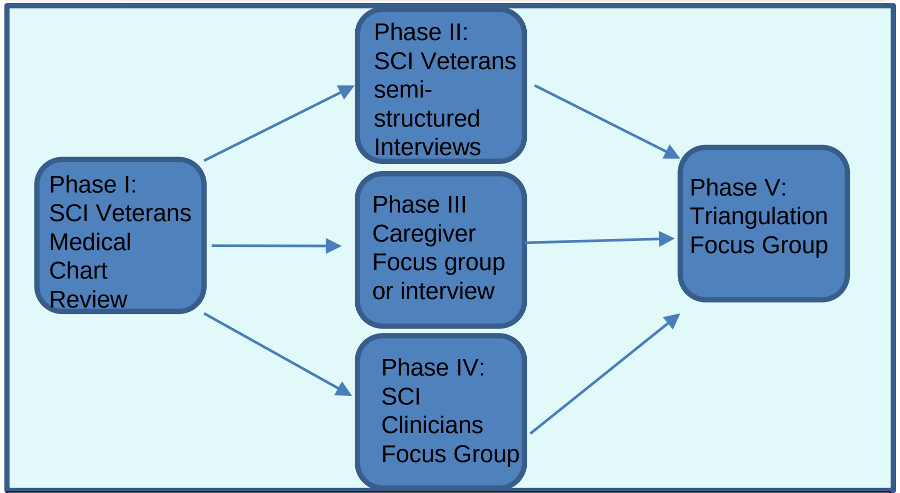
PI: Denise Fyffe, PhD **Org:** Kessler Foundation **Award Amount:** $598,000.00

Study Aim(s)

1. Describe SCI veterans' reasons for seeking service-connected versus non-service connected disability compensation and the factors that influence their choice;
2. Explore the impact of service-connected and non-service connected disability benefits on: a) health status; b) functional outcomes; c) QOL; and d) medical decisions (e.g., choice of VA SCI Center versus private sector).
3. Explore the impact of service-connection disability benefits on the SCI Veterans family caregivers and households.
4. Explore SCI clinicians' perspectives of the impact of service-connected and non-service connected SCI Veterans on the provision of adequate long-term healthcare and rehabilitation.
5. To develop a set of practice and policy recommendations about the impact of service-connected and non-service connected SCI Veterans to clinical and policy guidelines, family interventions, caregiver training and patient education programs.

Approach

Using a community-based participatory design, three qualitative data collection methods (i.e., medical chart reviews, semi-structured interviews and focus groups) will be implemented over sequential phases of qualitative data collection.



Phase I: SCI Veterans Medical Chart Review

Phase II: SCI Veterans semi-structured Interviews

Phase III Caregiver Focus group or interview

Phase IV: SCI Clinicians Focus Group

Phase V: Triangulation Focus Group

Accomplishments: Preparation to launch the study is complete; Community Advisory Board contributed to content of data collection for Phase I to Phase IV; Data collection instruments developed for Phase I to III; Data collection and quality checks initiated.

Timeline and Cost

Activities CY	15	16	17	18
Conduct chart review			🟩	🟩
Complete semi-structured interviews			🟩	🟩
Complete family caregiver and SCI clinician focus groups			🟩	🟩
Evaluation focus groups				🟩
Estimated Budget ($598,000.00)	138,951.00	129,341.00	148,226.00	173,119.00

Updated: 10/29/2019

Goals/Milestones

CY15 Goal – Prepare to launch the study

- ✓ Initiate research team meetings to plan study procedures and initiate develop the content of the data collection instruments

CY16 Goals – Prepare to launch study

- ✓ Standardize study operating procedures across study sites
- ✓ Initiate Phase I data collection

CY17 Goal – Data collection and ensure data quality

- ✓ Complete Phase I data collection; initiate data collection for Phase II, III and IV as well as ensure data quality checks are in place

CY18 Goal – Complete data collection

- ✓ Complete data collection

CY19 Goal – complete data cleaning, analysis and dissemination

☐ Complete data collection, data cleaning, analysis and dissemination

Comments/Challenges/Issues/Concerns

- Timelines change due to administrative issues, including securing a transcription company and accessing data

Budget Expenditure to Date

Projected Expenditure:: $598,000.00

Actual Expenditure $589,638.00

Protocol

Spinal Cord Injury Veterans' Disability Benefits, Outcomes, and Health Care Utilization Patterns: Protocol for a Qualitative Study

Denise C Fyffe[1,2], PhD; Joyce Williams[3], MSW; Paul Tobin[4], MSW; Carol Gibson-Gill[2,3], MD

[1]Kessler Foundation, Spinal Cord Injury/Outcomes and Assessment Research Center, West Orange, NJ, United States
[2]Rutgers, New Jersey Medical School, Newark, NJ, United States
[3]VA New Jersey Health Care System, Spinal Cord Injury and Disorders Service (128), East Orange, NJ, United States
[4]Quality of Life Advisors, Fort Myers, FL, United States

Corresponding Author:
Denise C Fyffe, PhD
Kessler Foundation
Spinal Cord Injury/Outcomes and Assessment Research Center
1199 Pleasant Valley Way
West Orange, NJ
United States
Phone: 1 973 324 3573
Email: dfyffe@kesslerfoundation.org

Abstract

Background: An estimated 42,000 people currently living with chronic spinal cord injury (SCI) are veterans. SCI was a common combat-related injury in the World Wars and Vietnam era and now affects more than 11% of military personnel injured in Operation Iraqi Freedom and Operation Enduring Freedom. The Veterans Benefits Administration primarily offers financial compensation for disabilities sustained or re-aggravated during military service, called service-connected disability compensation. With the overwhelming cost of living with an SCI, this monthly financial compensation can provide service-connected veterans and their families with access to additional supportive resources (eg, assistive devices and personal aide) and maintain their quality of life (QOL). Little is known about personal, health, functional, and QOL outcomes associated with service-connected and nonservice-connected status for veterans living with an SCI.

Objective: The aim of this study is to compare the ways in which Veterans Affairs' (VA) service-connected and nonservice-connected status may be associated with health and functional outcomes, choice of health care provider, and overall QOL for veterans living with an SCI and their caregivers.

Methods: This cross-sectional qualitative study will gather data using retrospective chart reviews, semistructured interviews, and focus groups. After obtaining institutional review board (IRB) approval, purposeful sampling techniques will be used to recruit and enroll the following key stakeholders: veterans living with an SCI, family caregivers, and SCI health care providers. Concurrent data collection will take place at 2 sites: Veterans Administration New Jersey Healthcare System and Northern New Jersey Spinal Cord Injury System.

Results: This study was funded in July 2015. IRB approval was obtained by November 2016 at both sites. Enrollment and data collection for phase 1 to phase 4 are complete. A total of 69 veterans, 18 caregivers, and 19 SCI clinicians enrolled in the study. Data analyses for these phases are underway. In phase 5, the follow-up focus group activities are scheduled. The final results are expected by the end of 2019.

Conclusions: The factors that contribute to veterans living with SCI seeking and not seeking VA disability compensation benefits are not well understood in rehabilitation research. Triangulation of these data sources will allow us to compare, contrast, and integrate the results, which can be used to develop clinical guidelines, caregiver training, and patient education programs.

International Registered Report Identifier (IRRID): DERR1-10.2196/14039

(JMIR Res Protoc 2019;8(10):e14039) doi: 10.2196/14039

KEYWORDS

veterans; spinal cord injuries; health care

Introduction

Overview

Spinal cord injury (SCI) is among the most devastating and disabling medical conditions affecting wounded members of the military [1-3]. The Department of Veteran Affairs (VA) is the single largest SCI comprehensive health care provider in the nation [4]. There are approximately 42,000 veterans with SCI eligible to receive care at the VA health care facilities [4]. There is also an unknown number of veterans who sustained an SCI following military service that have never used the VA but are eligible to receive health care from the VA. In addition, a portion of these veterans may be entitled to VA disability compensation and ancillary benefits. Veterans Benefits Administration (VBA) disability compensation benefits are designed to provide financial compensation for disabilities sustained or exacerbated during military service as well as secondary disabilities, which are later causally connected to disabilities that incurred during military service; functional deficits that are incurred or aggravated by military service are adjudicated by the VBA as *service-connected* [5,6]. For example, upon leaving the military, a veteran with a lower back injury applies for, and is adjudicated by VBA as having, a service-connected lower back injury. Later in life, the veteran's spinal cord develops a syringomyelia at the initial level of injury causing a SCI and further functional deficits, which can be adjudicated by VBA as a service-connected disability as well.

As the cost of living with an SCI can be insurmountable, the monthly financial compensation provided to service-connected veterans living with SCI through the VBA can be used to offset the loss of wages. In addition, veterans who are service connected specifically for their spinal cord condition (ie, loss of use feet or hands) may also qualify for additional grants funded through the VBA. These grants promote functional independence by providing resources for the aid and attendance required to maintain the veteran in the least restrictive setting; for example, a VA automobile allowance or specially adapted housing grant where the goal is to help veterans participate in their home life, employment, and social activities that might otherwise be inaccessible and maintain positive quality of life [7,8-10].

Despite VA's efforts to reduce the financial burden associated with successful rehabilitation, independent living, and community integration through disability benefits, a portion of veterans living with SCI have nonservice-connected disabilities because their disabilities were not incurred or aggravated by their military service [5,6]. On the basis of our literature review, there are no studies to date that have compared the impact of having additional financial resources provided to service-connected veterans living with SCI with nonservice-connected SCI-veterans who do not have these additional financial resources. This is a notable oversight because the views and experiences of the service-connected and nonservice-connected veterans living with SCI may be an invaluable source of insight to the VBA disability compensation program's effectiveness beyond the mere provision of additional financial resources. Using a community-based participatory design, the proposed study intends to address this gap using qualitative research methods to compare the impact of service-connected status on veterans' health status, functional outcomes, QOL, family and household, and choice of rehabilitation or medical facilities (ie, VA center or non-VA).

Background

The Department of Veterans Affairs (VA) estimates approximately 450 newly injured veterans and active-duty members receive rehabilitation at VA's SCI centers annually [4]. Results from an analysis of the Joint Theater Trauma Registry found the most common combat-related cause of spinal injuries during the Global War on Terrorism are explosions, which account for more than half of the cases, followed by motor vehicle accidents and gunshot wounds [1,11,12].Reports based on data from the National Spinal Cord Injury Database (NSCID) estimate that the average lifetime costs for a 25-year-old individual with high tetraplegia to be more than 3 million dollars, excluding additional opportunity costs such as lost wages, benefits, and productivity [13]. A disproportionate number of individuals living with SCI (62.7%) reside in households with an annual income of US $25,000 or less, and the NSCID reports that only 11.5% of persons with SCI report being employed 11-year after injury [14]. The evidence that socioeconomic disadvantage is common among persons with SCI suggests that this group is at increased risk for poorer health and functional outcomes, given the pervasive negative relationship between socioeconomic disadvantage and health and functional status [15]. Furthermore, these indicators of disadvantage may be exacerbated by the complexity of military service among veterans living with SCI, such as comorbid traumatic brain injury, pain, and posttraumatic stress disorder (PTSD) [16], suggesting that an examination of the provision of financial resources for veterans living with SCI to support health outcomes, functional independence, and QOL is warranted.

The primary goal of VA SCI and Disorders (SCI/D) services is to restore functioning, reduce secondary complications, and promote the health and sustainability of functional independence to maximize QOL after injury [17]. The VA SCI/D System of Care is referred to as a *hub and spoke* system. The VA SCI/D System of Care includes 25 regional SCI/D Centers (known as *hubs*) that provide comprehensive range of care including, inpatient and outpatient rehabilitation, specialty care, and coordinated lifelong continuum of care delivered by interdisciplinary teams [17]. After rehabilitation, most veterans living with SCI return to live in the community [17]. Thus, independent living, community reintegration (eg, functional independence, social participation, and employment access), and QOL are top priorities for VA SCI center rehabilitation [14,17].

The SCI Model Systems (SCIMS) are specialized programs of care in SCI that gather information and conduct research with the goal of improving long-term functional, vocational, cognitive, and QOL outcomes for individuals with SCI. SCIMS, sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, US Department of Health and Human

Services, supports innovative projects and research in the delivery; demonstration; and evaluation of medical, rehabilitation, vocational, and other services to meet the needs of individuals with SCI. The Northern New Jersey Spinal Cord Injury System (NNJSCIS) was established as a SCIMS in 1990. The NNJSCIS provides a comprehensive continuum of state-of-the-art care for persons with spinal cord injury and their families from the time of injury through rehabilitation and return to the community.

Veterans Disability Compensation Benefits

VA provides monthly disability compensation benefits to veterans who develop medical conditions and disabilities related to military service; that is, who are deemed *service connected* [5,6,18-19,20]. Veterans seek service connected disability compensation benefits when: (1) they are discharged from the military because of a disability that was incurred or aggravated during military service; (2) a disability manifests itself after the veteran leaves the military but the veteran believes he can prove that its origins occurred in the military (ie, low back pain because the veteran was an infantryman who carried a heavy ruck sack on multiple deployments); (3) a veteran has an earlier service connected disability that results in a worsened disability (eg, service connected knee injury leads to a fall resulting in a SCI); or (4) a veteran is diagnosed with a condition that is presumptively considered service-connected (ie, if a veteran is diagnosed with amyotrophic lateral sclerosis [21] following their military service, it is presumptively considered service-connected and compensable). To qualify for disability compensation benefits, veterans have to submit an disability compensation application and complete a medical assessment to ascertain the functional impact of their disabilities and its impact on a veterans' *average impairment in earning capacity* [5,6,22-23,18-19]. On the basis of the VBA Schedule for Rating Disabilities, disability ratings range from 0% to 100% in 10% increments (ie, *scheduler ratings*), with a higher percentage of rating equaling a greater functional impairment and amount of disability compensation awarded. Typically, a VA disability rating is derived from an algorithm that combines the individual scheduler ratings of each compensated disability [5,6]. Therefore, two 10% disability ratings do not equal 20%. The algorithm takes into account the number and severity of each scheduler rating and attempts to calculate the overall impact on average earning capacity. Typically, veterans with service-connected SCIs that impact their ability to walk and cause neurogenic bowel and bladder have scheduler ratings of 100% for bilateral loss of use of lower extremities, 60% for neurogenic bladder, and 60% for neurogenic bowel [5,6]. The algorithm combines these ratings to 100% and awards maximum VA disability compensation benefits [5,6]. Unlike Social Security Disability Insurance, which by definition can only be awarded when a disability results in the inability "to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months," VA disability compensation benefits are tax-exempt and not automatically discontinued if the veteran returns to work [5,6,22-23,18-19].

Research Problem

Little is known about the differential impact of service-connected status on the health status, functional outcomes, QOL, and health care utilization patterns of veterans living with SCI. Interestingly, veterans service-connected for PTSD have been found to report high rates of medical impairment, psychiatric symptomatology, and utilization of medical and mental health services [22,23,18]. Furthermore, veterans with PTSD sought service-connected disability compensation of internal factors (eg, tangible needs, need for the problem identification and clarification, and justification and legitimization of *invisible wounds*) and external factors (eg, encouragement from trusted others and professional assistance associated with seeking disability benefits) [19]. These findings suggest there may be a range of factors to consider that may differentially impact veterans living with an SCI based on their service-connected status.

The proposed study intends to address this gap in the literature using qualitative research methods to explore the perspectives of service-connected and nonservice-connected veterans living with SCI, family caregivers as well as SCI clinicians about factors that contribute to these veterans' health status, functional outcomes, and health care utilization. On the basis of the aforementioned literature, individual/personal factors, socioeconomic, family, and health system factors will be explored. Individual factors such as demographic characteristics (eg, age), cultural beliefs, socioeconomic status (eg, education and income), and health risk behaviors (eg, smoking and alcohol use) have been found to the impact on health status, functional outcomes, and health care utilization in veterans living with SCI [24]. Family caregivers provide assistance that is critical to sustaining health status, functional gains, and access to health care services as Veterans living with SCI return to the community and will provide information about household/community barriers observed across service-connected and nonservice-connected veterans living with SCI [25-27]. SCI health care providers, such as physicians, nurses, social workers, and occupational and physical therapists will provide insights into clinical factors that could contribute to health status, functional outcomes, and health care utilization among veterans living with SCI. Given the high cost of living with an SCI, understanding veterans' reasons for seeking or not seeking service-connected disability compensation benefits will provide insights about the ways in which veterans' manage their health, functioning, health care, and QOL.

Conceptual Model

This investigation will be guided by the framework of the International Classification of Functioning, Disability, and Health (ICF) [25,26] to examine how service-connection status influences health, function, and health care utilization patterns among veterans living with an SCI. The ICF model conceptualizes disability as an interaction between impairment, functioning, personal factors, and the environment. The ICF can be used to identify, mitigate, or remove societal barriers to full participation of persons with SCI [27-29]. Functioning and disability are viewed as a complex interaction between the impairment of individual, environmental (ie, contextual), and personal factors. Within this framework, SCI is a condition that most often results in impairments such as permanent paralysis. Paralysis then leads to secondary complications, functional limitations, and restrictions to community participation over time. The ICF model serves as a rehabilitation model that will be used to guide the data collection, measuring project outcomes, and designing of clinical guidelines, family interventions, caregiver training, and patient education programs (Figure 1).

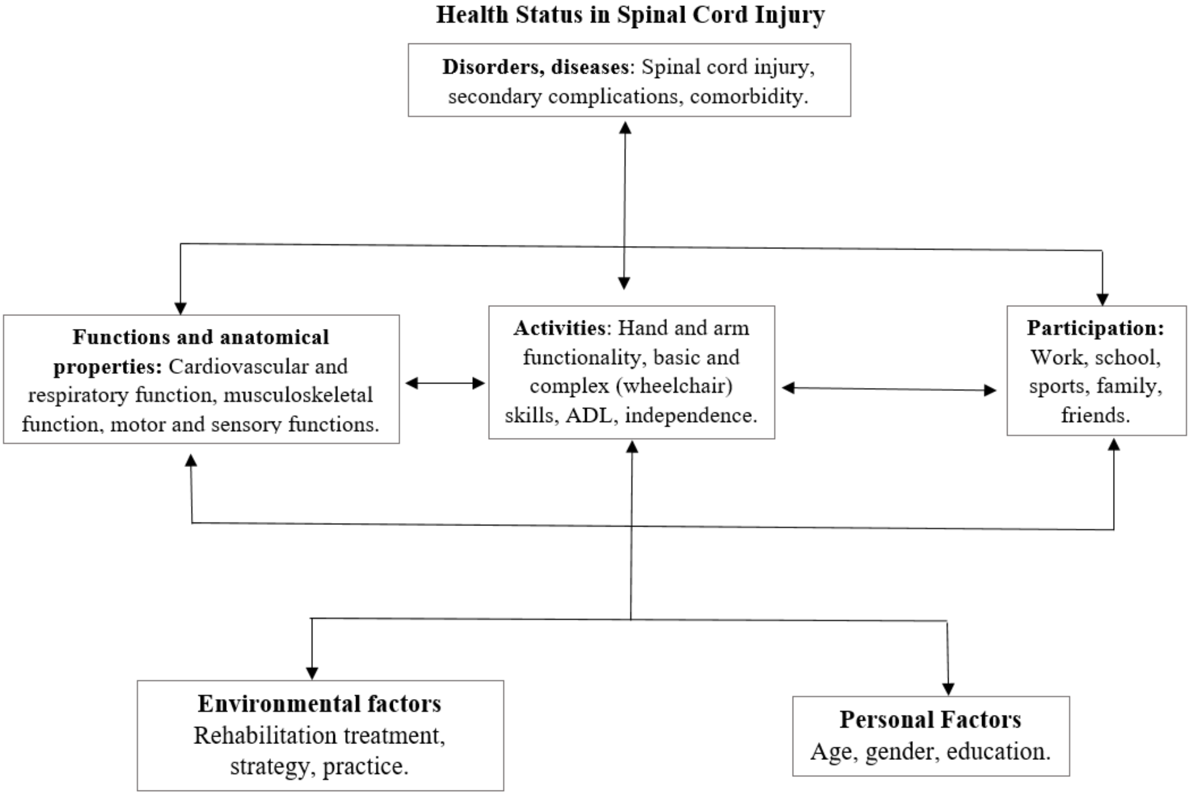
Specific Aims

The proposed project will use qualitative methods to examine the factors associated with outcomes for service-connected and nonservice-connected SCI. Qualitative methods have the advantage of allowing us to address these aims in a manner that is meaningful to individuals who are actively involved in SCI veteran rehabilitation: veterans living with SCI, family caregivers, and SCI clinicians. We propose the following aims:

1. To describe veterans living with SCIs' reasons for seeking versus not seeking service-connected disability compensation and the factors that influence their choice.
2. To explore the impact of service-connected disability compensation on health status, functional outcomes, QOL, and medical decision making (eg, choice of VA SCI Center versus private sector).
3. To explore the impact of service-connected disability compensation on the family caregivers and households of veterans living with SCI.
4. To explore SCI clinicians' perspectives on the impact of service-connected disability compensation status on the provision of adequate long-term health care and rehabilitation for veterans living with SCI.
5. To develop a set of practice and policy recommendations about the impact of service-connection status of veterans living with SCI on clinical and policy guidelines, family interventions, caregiver training, and patient education programs.

The proposed work is significant because it will provide new knowledge about veterans living with SCI with and without service connected disability compensation in the realm of family caregiver support, access to community resources, personal factors, and health behaviors, including patient-provider relationships and their impact on health status, functional outcomes, and QOL. The findings will describe areas of care considered priorities for veterans living with SCI and families that must be clearly integrated into clinical care to support the successful maintenance of health status, functional outcomes, and QOL.

Figure 1. International Classification of Functioning model for spinal cord injury (adapted from de Groot et al, 2009 [27]). ADL: activities of daily living; ICF: International Classification of Functioning, Disability and Health; SCI: spinal cord injury.



Methods

The study protocol, research team and data collection instruments were reviewed and approved by the institutional review board (IRB) at each study site as well as US Army Medical Research and Materiel Command`s Office of Research Protections, Human Research Protection Office.

Research Design

This cross-sectional qualitative study will use a community-based participatory approach to examine the reasons for seeking disability compensation benefits, factors associated with outcomes, and choice of health care facility among veterans living with SCI with and without service-connected disability benefits. Community-Based Participatory Research represents a collaborative process between researchers and community partners; builds on the unique strengths, knowledge, and resources within a given community by employing local knowledge in the understanding of health problems and their potential solutions; and facilitates collaboration throughout all phases of the research [30].We will collaborate and gather data from veterans living with SCI, caregivers, and SCI professionals who will serve as *experts* to explore the health status, functional outcomes, and QOL of veterans living with SCI with different types of disability benefits and who decide to receive their health care from VA centers and non-VA.

Interdisciplinary Project Team

To achieve these aims, we assembled a highly productive and interdisciplinary team of SCI/D researchers and community advisors with expertise in qualitative research methods, VA SCI *hub and spoke* system of care, private care sector of SCI care, caregiving, and SCI research.

Participants

The study will collect data from 3 groups of participants involved in sustaining the health status, functional independence, and QOL of veterans living with SCI who are impacted by the type of disability benefits and health care utilization patterns:

Spinal Cord Veterans

An equal number of veterans living with SCI receiving clinical services or who have previously participated in research at the East Orange Campus of the VA New Jersey Health Care System (VANJHCS) or Northern New Jersey SCI Model System (comprised the Kessler Foundation and Kessler Institute for Rehabilitation) will participate in phase 1 (n=15 per site) and 2 (n=30 per site) of the study (described below).

Inclusion Criteria

Inclusion criteria are being male, veterans (or served on active duty service in the US Armed Forces), at least 18 years of age, SCI that occurred at least 1 year ago, and receiving health care/rehabilitation at the participating VANJHCS and/or a participating Spinal Cord Injury Model System site or Spinal Cord Injury Model System (SCIMS).

Exclusion Criteria

Exclusion criteria are inability to communicate because of neurological impairment (eg, dementia or aphasia); identifying as a female. We limited the scope of the study to patients to male veterans living with SCI because there are not likely to be sufficient numbers of female veterans living with SCI to be able to recruit a meaningful sample of them, given a larger proportion of people with SCI and veterans are males and thus beyond the scope of this project.

Spinal Cord Injury Veteran Family Caregivers

SCI often results in physical limitations such that receiving assistance from others is critical to maintaining health and facilitating full societal integration. The help received ranges from assistance with basic daily activities such as bowel and bladder management and dressing, as well as instrumental activities of daily living, including managing household finances, shopping, or transportation. In the United States, most home care is provided through informal mechanisms by family members [31], and almost 70% of people with SCI receive some form of assistance and support from family members [32]. One individual in a family frequently assumes most or all the responsibilities of caring for a person with a disability [33], and this responsibility can carry with it several physical, emotional, social, and economic risks. We will recruit a sample of 10 SCI veteran family caregivers from each site who have provided care on a daily basis, for at least 6 months, to SCI, and preferably, these family members identify as the *primary* caregivers. Family caregivers who may be eligible to participate in the focus groups or interviews will be identified by clinical staff (social workers, therapists, and others) or an SCI veteran who participated in a semistructured interview. A member of the research team will contact the family caregiver to inform them about the study and determine if they meet the eligibility criteria to provide additional information and make arrangements to obtain informed consent before the start of focus group or interview data collection.

Spinal Cord Injury Veteran Clinicians

Clinicians' perceptions are important because they may affect patient-provider relationships, the course, and the outcome of treatment. Clinicians have knowledge of the medical and functional consequences of SCI and experience providing training to veterans living with SCI and their family caregivers to plan for adjusting to home life and community reintegration. SCI clinicians at each participating center will be informed of the study through written (flyers and emails) and oral communications with local study leaders and/or supervisory staff. We will recruit a sample of 10 clinicians at both sites that includes staff members who have experience providing direct care or services to veterans living with SCI at each of the research sites. The SCI clinical staff will include physiatrists, nurses, social workers, physical, recreation, and occupational therapists who have at least 2 years of experience providing care to SCI. Clinicians who are interested in participating and wish to be contacted by the research team will receive additional information and, if interested, give informed consent before the start of focus group data collection.

Each group of participants has real-world experiences and clinical knowledge that will inform the content of the key practice recommendations that can be readily integrated into clinical guidelines, family interventions, caregiver training, and patient education programs.

Study Sites

Two study sites that serve veterans living with SCI in New Jersey will conduct the proposed study: VANJHCS and Northern New Jersey Spinal Cord Injury System. A description of each research site is provided in Multimedia Appendix 1: facilities, existing equipment, and other resources. These sites were selected for their access to diverse communities of veterans living with SCI served by the respective research institutions. Each site has an average of 190 to 429 veterans living with SCI in their respective patient registries.

Sampling Strategy and Recruitment

After obtaining approval from the IRB at the study sites, purposeful sampling strategies will be used to identify and recruit potential study participants. A research coordinator (RC) will recruit potential participants using advertisements, brochures, and referrals from SCI registries at each collaborative site. If we do not get an adequate recruitment response, we will implement the snowball recruitment technique that involves asking participants to inform and encourage friends, colleagues, and other peers to participate [34].

In recent years, data saturation has become the gold standard by which purposive sample sizes are determined in qualitative research [35]. Theoretical saturation is achieved when focus groups or interviews do not generate novel ideas. The sample sizes proposed for each study phase described below are based on minimum sample size recommendations for common qualitative study designs [36]. Furthermore, our sampling strategy will be flexible, evolving as the study progresses through the 4 phases, until the point of redundancy in emerging themes is reached to meet the purposes of the study.

Once each participant completes oral and written informed consent and is scheduled for interview or focus group session, he/she will receive a telephone reminder 2 weeks before the interview or focus group as well as a written letter 1 week beforehand. The day before the event, the consultant will make 1 last round of confirmatory phone calls. Participants will be compensated for their time. In addition, to maintain enrollment and participation, we will provide transportation cost for a portion of veterans living with SCI and family caregiver on an as-needed basis.

Data Collection

Three methods of qualitative data will be collected: chart review, semistructured interviews, and focus groups. These 3 qualitative data collection methods will be implemented over 4 phases of sequential qualitative data collection outlined in Table 1. The content of the chart reviews, interviews, and focus groups will be stratified based on disability benefits. The structure and content of questions will be modified based on joint planning with the community advisory board (CAB) during the course of the project. Of particular interest is how these groups *independently* interpret the reasons and impact of the disability benefits on veterans living with SCIs’. Results from each phase will be analyzed separately and then merged to inform the content of the subsequent phases as well as the set of practice recommendations that can be readily integrated into clinical guidelines and family interventions. Multimedia Appendix 2 provides detailed description of sample items from the data collection instruments.

Table 1. Research plan.

Phase	Data collection	Purpose	Data source
I	Chart review	Prepare and supplement data gathered in subsequent phases	Medical records
II	Semistructured interviews	Exploring SCI[a] veterans’ understanding and perceptions of VA[b] disability compensation benefits	SCI
III	interviews/focus groups	Identify SCI family caregivers’ perspectives about the impact of disability benefits on the household	SCI family
IV	Focus groups	SCI clinicians’ perspectives of the impact of VA disability benefits on SCI and provision of adequate long-term health care and rehabilitation	SCI
V	Focus groups	Develop key elements for clinical practice recommendations	Triangulation of study findings, feedback from service

[a] SCI: spinal cord injury.

[b] VA: US Department of Veterans Affairs.

Phase I: Chart Review

The RC will be trained to use a standardized chart abstraction instrument to gather demographic, clinical, and disability benefits data. The chart review will be designed to help prepare and supplement data gathered in subsequent phases by providing data that will (1) inform the development of discussion questions for the participant interviews and focus groups; (2) confirm the veterans living with SCI disability status and rating; and (3) documentation of health status, functional information, and patient/family education logs gathered during the most recent annual evaluation of 30 veterans living with SCI (15 per site). An annual evaluation was defined as a *comprehensive annual history/physical exam with specialty assessments*, offering an annual evaluation is mandated for patients with SCI in the Veterans Health Administration (VHA) [17].

Phase II: Semistructured Interviews

Semistructured interviews will be aimed at capturing service-connected and nonservice-connected veterans living with SCI perspectives on ways in which their financial compensation (or lack thereof) impacts their health status, functional independence during community reintegration, QOL, and their utilization of health care. The sample will be equally split between study sites (n=30) veterans. We will modify items from the benefits coverage inventory, a measure that has been used in previous research to assess rehabilitation/independent living benefits received after discharge in 5 areas: housing, personal care assistant, transportation; outpatient therapies (eg, physical therapy, occupational therapy, and vocational rehabilitation), and equipment (durable and nondurable). The measure asks about who pays for these items (self, insurance, or other). We will work with the CAB to develop semistructured interview questions that relate to service-connected disability benefits. The semistructured interview will discuss veterans living with SCIs' likes and dislikes of the being service-connected or nonservice-connected—their perceptions about whether disability benefits may be viewed as a barrier to independence, and difficulties with bureaucracy for some veterans living with SCI. The interview will ask veterans living with SCI to express their experiences about unexpected barriers associated with seeking service-connected financial compensation. Key questions will focus on their health status, maintenance of their functional independence during community reintegration, health care, and rehabilitation experiences. The individual semistructured interview allows for rapport and confidence building at a sensitive time after injury so that more honest opinions and attitudes may be revealed more readily than in a group setting. The interviewer can answer respondent questions, probe for additional answers, and observe visual cues. To facilitate access to veterans living with SCI who are unable to come to the research site for an interview, we will use the VA's real-time video health tool—Clinical Video Telehealth that is a technology that is frequently used in the VA to promote video communication between patients and providers (see Multimedia Appendix 3—Facilities, Existing Equipment, and Other Resources). To ensure quality data assurance, interviews will be audiotaped and transcribed. After the interview is completed, the RC and research assistant will summarize their notes and review the results with the principal investigator (PI). Spot checks of the transcripts comparing them with the audiotapes will be done to ensure accuracy of the transcripts.

Phase III: Spinal Cord Injury Veteran Family Caregivers

SCI family caregivers provide assistance that is critical to sustaining health status, functional gains, and access to health care services as veterans living with SCI return to the community and will provide information about household/community barriers observed across service-connected and nonservice-connected veterans living with SCI. We give family caregivers the option to participate in a caregiver focus groups or individual semistructured interviews. The qualitative data collection methods will be used to ascertain SCI veteran family caregivers' perspectives on the impact of disability benefits on their family life, including household finances, the health of SCI veteran as well as their own health, and the provision of health care/rehabilitation to sustain the functional independence of the SCI. Caregivers will also be asked to provide suggestions about potential solutions to the problems they identify to facilitate their efforts providing care to an SCI veteran that is service connected or not service connected.

Focus groups are an efficient way to collect data from several people simultaneously, and they explicitly use group interaction as part of the method [34]. Focus groups will allow us to elucidate the shared experience and challenges of seeking disability benefits and the factors associated with outcomes and choice of health care facility among veterans living with SCI with and without service-connected disability benefits. This recruitment strategy will account for nonattendance and ensure optimum focus group size and participant comfort [34]. Multimedia Appendix 2 gives a draft of the focus group script.

The RC will take field notes on a structured data recording sheet, based on the focus of group script/interview guide. The field notes will include key points, notable quotes, and important observations such as silent agreement, body language, group mood, and ironic or contradictory statements. Each focus group will be recorded and transcribed, but anonymity will be maintained. The focus groups will be recorded with a password-enabled digital recorder, and we will transfer all the recordings to the secure VA network after each interview is completed. At the end of each focus group, the PI will give a brief oral summary of critical points that the participants can verify, amend, or change. The PI and RC will meet for a debriefing immediately after each session to share their perceptions of first impressions, critical points, and notable quotes and to highlight and contrast findings from earlier focus groups. This debriefing will also include any notable circumstances that influenced the discussion, resolution of questions, and potential modifications for subsequent groups and/or interviews.

Phase IV: Spinal Cord Veterans' Clinicians

We will conduct focus groups with SCI clinical staff from the Veterans Administration New Jersey Healthcare System and SCIMS health care systems. The focus groups will be conducted with approximately 10 interdisplinary SCI clinicians per group to provide insights into the following: (1) clinical factors of veterans living with SCI who seek different types of disability compensation benefits (ie, service connected and others are nonservice connected); (2) describe their perception about the relationship between disability benefits and health status, functional outcomes and health care utilization among veterans living with SCI; (3) identify VA and private-sector health care system issues related to disability compensation benefits, which are obstacles for veterans living with an SCI; and (4) identify solutions to address these concerns.

Phase V: Developing Practice and Policy Recommendations

Qualitative Data Analysis Plan

To design a useful set of practice recommendations, we will analyze results from phases I to IV separately and then merge them to prepare the content materials for phase V. The chart review, interview, and focus group data will be prepared for analysis by converting the raw data (eg, field notes) into partially processed data (eg, write-ups and transcripts), which will then be coded and subjected to an analytic theme. The analysis will focus on the key research questions and include the following steps:

1. Read each transcript in an editing style to augment an initial codebook template developed from the ICF guidelines and interview guide.
2. Read and reread highlighted portions to develop keywords (themes, patterns, or categories).
3. Divide the themes, patterns, and categories into groups by the research questions.
4. Examine the convergence/divergence by completing the following steps:

Convergence will be examined by determining what themes fit together to develop the internal homogeneity and external heterogeneity.

Internal homogeneity will be determined by analyzing the themes to see which are more similar, and external heterogeneity was determined by analyzing the themes to see which ones are distinctly different from each other [37].

These processes will enhance the credibility of the research. Divergence will reveal some of the patterns within the categories and helps to make connections among the themes for categorical saturation [37].

Qualitative data collected in phases I to IV will generate its own findings to add additional information to our understanding about the reasons veterans living with SCI seek different types of disability benefits and how these factors that are associated with health status, functional outcomes, and QOL. Triangulation is methodological approach that contributes to the validity and reliability of qualitative data collection when multiple method and sources are employed [38]. Triangulation will allow us to compare, contrast, and integrate the results from the chart reviews, veterans living with SCI, family caregivers, and SCI clinicians. Triangulation from the focus group and interview data will also allow us to ensure results are being confirmed across data sources and identify what is being uniquely provided by different data sources. Investigator triangulation, which consists of multiple—rather than single—observers, will be used to strengthen the validity and credibility of the qualitative findings observed in each phase of the study [38]. A very large amount of raw data will be generated; therefore, narrative data will be stored and analyzed using QSR International's NVivo 12 software. This type of software facilitates thematic coding, interrater reliability, and correlation of themes with demographic characteristics. NVivo can also be used with Excel spreadsheets to generate matrices that demonstrate relationships between variables and themes.

Developing Practice and Policy Recommendations

Using the themes generated from the qualitative analyses, we will work with the CAB to summarize to identify the most frequently cited factors (ie, problems and solutions) that impact veterans living with SCIs' decision to seek service-connected disability benefits (ie, those that are mentioned by more than 1 data source) and across samples of participants—a process that is known as *group-to-group validation* [34].

There are a number of steps outlined in the literature used to develop targeted recommendations for clinical guidelines, developing recommendations for patient and family educational resources, and policy-level interventions. First, the research team will generate a summary of the most frequently cited factors identified from the data as recommendations to the CAB. Examples of potential interventions include revisions to existing patient and family education material related to programs and services available from the VA for veterans with SCI; educational interventions for SCI clinicians to make them more aware of resources available from the VA that are correlated with positive clinical practice outcomes for veterans with SCI veteran, and their families, caregivers, and other clinicians; procedures to help clinicians identify veterans living with SCI at civilian hospitals and connecting these veterans and their families with knowledgeable VA advocates (eg, VA SCI social worker or veteran service organization) and VA disability compensation and health care resources.

Second, the CAB and research team will have monthly consensus meetings, which will be used to evaluate aspects of the most frequently cited individual, family, SCI clinician, and systemic factors generated from the data: importance to veterans living with SCI and modifiability. Determination of importance can be obtained in several ways, such as the CAB rating on the degree of importance, and assessing socially significant implications of the qualitative findings. The CAB and research team will collaboratively rate the modifiability of the individual, family, SCI clinician, and systemic factors from the qualitative data by asking the question, “Can this problem easily be addressed?” or “Can this solution be implemented pragmatically?” The collaborative will rate these individual, family, SCI clinician, and systemic factors as (1) factors that can be completely changed, (2) factors that may be modified, but we are unable to change them completely, and (3) factors that are nonmodifiable. Third, the CAB and research team will select *targets of change*. After identifying the factors that are both important and modifiable, the CAB and research team will decide which factors will be targeted for recommendations for interventions. Finally, the CAB and research team will select promising strategies or key recommendations to develop an intervention action-point document. The intervention action-point document will be a road map toward the operationalization of an educational intervention for SCI, families, SCI clinicians, and policy recommendations for the VBA.

Content of the intervention action-point document will be evaluated assessed for their appeal, clarity, and appropriateness for the target users. We will recruit veterans living with SCI and family caregivers who participated in phases I to III. We will recruit approximately 5 veterans living with SCI and 5 family caregivers. Veterans living with SCI and family caregivers will be asked if they are willing to participate in future groups or interviews. Members of the research team will recruit those who agreed using personal phone calls. If we do not get an adequate response from the previously identified participants, advertisements, brochures, word of mouth, and the aforementioned snowball technique will be used. An honorarium will be offered to compensate participants for their time and transportation.

Results

The project was funded in July 2015, and recruitment was completed in October 2018.

A total of 69 male veterans living with an SCI participated in medical chart review and interview phases of the study. The mean age of the sample was 59.5 years (SD 14.8; range 23-86). Most of the veterans self-identified as non-Hispanic white (61%, 42/69), married (52%, 36/69), had some college education (80%, 55/69), and unemployed (93%, 64/69). In terms of military experience, approximately one-third served in the army (39%, 27/69) and primarily in the Vietnam era (32%, 22/69). The majority of veterans sustained their injury after military service (75%, 52/69), and were living with paraplegia (53%, 37/69) for an average of mean 15.0 years (SD 13.0. Almost two-thirds; 64%, 44/69) of the veterans self-identified as nonservice connected and 36% (25/69) were service connected for SCI or another disability (eg, PTSD). A total of 18 caregivers participated in focus groups and interviews at the 2 sites. All of the caregivers were females, the mean age of caregivers was 64.8 years (SD 10.8) and reported caregiving for their loved one for approximately, 15.9 years (SD 11.4). A total of 9 SCI clinicians participated in a focus group at Veterans Administration New Jersey Healthcare System and 10 at the SCIMS site. Comparable clinical professions (eg, psychiatrist, nurse, and therapists) were represented in each focus group and average of 11.5 years (SD 8.8) working in their current positions.

Preliminary content review of narrative data suggests that veterans living with an SCI and caregiver participants varied in their reasons why they did not apply for VA disability compensation, including a lack of knowledge and misinterpretations about the VA disability compensation eligibility and health care coverage from the VBA and VHA, respectively.

Discussion

This qualitative study will use a community-based approach to derive information from veterans living with SCI, family caregivers, and SCI clinicians about their day-to-day experiences with being service connected or nonservice connected status. Of particular interest is how these groups *independently* interpret the reasons and impact of service-connected compensation (or lack thereof) on the health status, functional outcomes, QOL, and health care utilization of veterans living with SCI. Preliminary findings suggest a small proportion of participants receive VA service-connected disability compensation benefits. Participants' responses indicate that veterans living with an SCI and their caregivers may not be fully aware of their eligibility for VA disability compensation, making it more difficult to make an informed decision about pursuing VA disability compensation benefits. To make an informed decision about eligibility for VA disability compensation benefits, veterans living with SCI should be connected with an experienced veterans benefits advocate (ie veterans service officer). Study findings will be used to generate a set of practice recommendations to the clinical guidelines, family interventions, caregiver training, and patient education programs that can be tested in a future large-scale multisite quantitative study to devise targeted community-based interventions.

Acknowledgments

The authors would like to thank the research team who contributed to the design of this project: CAB members Amy Rupert, Angela Smith, Katie Travia, Christopher M Cirnigliaro, William Hannigan, and Javier Robles.

This project was funded by the Office of the Assistant Secretary of Defense for Health Affairs through the Spinal Cord Injury Research Program under Award No. W81XWH-15-1-0278. The contents of this paper, including opinions, interpretations, conclusions, and recommendations are those of the author and are not necessarily endorsed by the Department of Defense.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Peer-reviewer report from the Department of Defense, United States of America.
[PDF File (Adobe PDF File)156 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Data collection instruments.
[PDF File (Adobe PDF File)129 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Facilities and resources.
[PDF File (Adobe PDF File)201 KB-Multimedia Appendix 3]

References

1. Blair JA, Patzkowski JC, Schoenfeld AJ, Rivera JD, Grenier ES, Lehman Jr RA, Skeletal Trauma Research Consortium (STReC). Spinal column injuries among Americans in the global war on terrorism. J Bone Joint Surg Am 2012 Sep 19;94(18):e135(1-e1359). [doi: 10.2106/JBJS.K.00502] [Medline: 22992883]
2. Patzkowski JC, Blair JA, Schoenfeld AJ, Lehman RA, Hsu JR, Skeletal Trauma Research Consortium (STReC). Multiple associated injuries are common with spine fractures during war. Spine J 2012 Sep;12(9):791-797. [doi: 10.1016/j.spinee.2011.10.001] [Medline: 22054909]
3. Possley DR, Blair JA, Freedman BA, Schoenfeld AJ, Lehman RA, Hsu JR, Skeletal Trauma Research Consortium (STReC). The effect of vehicle protection on spine injuries in military conflict. Spine J 2012 Sep;12(9):843-848. [doi: 10.1016/j.spinee.2011.10.007] [Medline: 22177925]
4. US Department of Veteran Affairs. 2009. VA and Spinal Cord Injury: Fact SheetURL:https://www.va.gov/opa/publications/factsheets/fs_spinal_cord_injury.pdf [accessed 2016-01-01]
5. Veterans Benefits Administration. 2013. Annual Benefits Report: Fiscal Year 2013URL:https://benefits.va.gov/REPORTS/abr/docs/2013_abr.pdf [accessed 2016-01-01]
6. US Department of Veteran Affairs. 2014. Health Care BenefitsURL:https://www.va.gov/opa/publications/benefits_book/Chapter_1_Health_Care_Benefits.asp [accessed 2016-01-01]
7. French DD, Campbell RR, Sabharwal S, Nelson AL, Palacios PA, Gavin-Dreschnack D. Health care costs for patients with chronic spinal cord injury in the Veterans Health Administration. J Spinal Cord Med 2007;30(5):477-481 [FREE Full text] [doi: 10.1080/10790268.2007.11754581] [Medline: 18092564]
8. Leduc B, Lepage Y. Health-related quality of life after spinal cord injury. Disabil Rehabil 2002 Mar 10;24(4):196-202. [doi: 10.3349/ymj.2007.48.3.360] [Medline: 11926260]
9. Scherer MJ. Outcomes of assistive technology use on quality of life. Disabil Rehabil 1996 Sep;18(9):439-448. [doi: 10.3109/09638289609165907] [Medline: 8877302]
10. Scherer MJ, Glueckauf RL. Assessing the benefits of assistive technologies for activities and participation. Rehabil Psychol 2005 Jul 8;50(2):132-141. [doi: 10.1037/0090-5550.50.2.132]
11. Blair JA, Patzkowski JC, Schoenfeld AJ, Rivera JD, Grenier ES, Lehman RA, Skeletal Trauma Research Consortium (STReC). Are spine injuries sustained in battle truly different? Spine J 2012 Sep;12(9):824-829. [doi: 10.1016/j.spinee.2011.09.012] [Medline: 22000726]
12. Blair JA, Possley DR, Petfield JL, Schoenfeld AJ, Lehman RA, Hsu JR, Skeletal Trauma Research Consortium (STReC). Military penetrating spine injuries compared with blunt. Spine J 2012 Sep;12(9):762-768. [doi: 10.1016/j.spinee.2011.10.009] [Medline: 22100206]
13. Jackson AB, Dijkers M, Devivo MJ, Poczatek RB. A demographic profile of new traumatic spinal cord injuries: change and stability over 30 years. Arch Phys Med Rehabil 2004 Nov;85(11):1740-1748. [doi: 10.1016/j.apmr.2004.04.035] [Medline: 15520968]
14. Krause JS, Saunders LL, DeVivo MJ. Income and risk of mortality after spinal cord injury. Arch Phys Med Rehabil 2011 Mar;92(3):339-345 [FREE Full text] [doi: 10.1016/j.apmr.2010.09.032] [Medline: 21353818]
15. Fyffe DC, Botticello AL, Myaskovsky L. Vulnerable groups living with spinal cord injury. Top Spinal Cord Inj Rehabil 2011;17(2):1-9 [FREE Full text] [doi: 10.1310/sci1702-01] [Medline: 23966760]
16. Ullrich PM, Smith BM, Poggensee L, Evans CT, Stroupe KT, Weaver FM, et al. Pain and post-traumatic stress disorder symptoms during inpatient rehabilitation among operation enduring freedom/operation Iraqi freedom veterans with spinal cord injury. Arch Phys Med Rehabil 2013 Jan;94(1):80-85. [doi: 10.1016/j.apmr.2012.07.018] [Medline: 22864017]
17. VA's Spinal Cord Injuries. 2011. Spinal Cord Injuries and Disorders System of Care URL:https://www.sci.va.gov/ [accessed 2016-01-01]
18. Sayer NA, Thuras P. The influence of patients' compensation-seeking status on the perceptions of veterans affairs clinicians. Psychiatr Serv 2002 Mar;53(2):210-212. [doi: 10.1176/appi.ps.53.2.210] [Medline: 11821554]
19. Sayer NA, Spoont M, Murdoch M, Parker LE, Hintz S, Rosenheck R. A qualitative study of US veterans' reasons for seeking Department of Veterans Affairs disability benefits for posttraumatic stress disorder. J Trauma Stress 2011 Dec;24(6):699-707. [doi: 10.1002/jts.20693] [Medline: 22109077]
20. Committee on Medical Evaluation of Veterans for Disability Compensation, Board on Military and Veterans Health, Institute of Medicine, National Academy of Sciences. In: McGeary M, Ford M, McCutchen SR, Barnes DK, editors. A 21st Century System for Evaluating Veterans for Disability Benefits. Washington, DC: National Academies Press; 2007.
21. US Government Publishing Office. Code of Federal Regulations URL:https://www.govinfo.gov/content/pkg/CFR-2011-title38-vol1/pdf/CFR-2011-title38-vol1-sec3-309.pdf [accessed 2019-08-30]
22. Frueh CB, Elhai JD, Gold PB, Monnier J, Magruder KM, Keane TM, et al. Disability compensation seeking among veterans evaluated for posttraumatic stress disorder. Psychiatr Serv 2003 Jan;54(1):84-91. [doi: 10.1176/appi.ps.54.1.84] [Medline: 12509672]

23. Frueh CB, Grubaugh AL, Elhai JD, Buckley TC. US Department of Veterans Affairs disability policies for posttraumatic stress disorder: administrative trends and implications for treatment, rehabilitation, and research. Am J Public Health 2007 Dec;97(12):2143-2145. [doi: 10.2105/AJPH.2007.115436] [Medline: 17971542]
24. Kazis LE, Miller DR, Clark J, Skinner K, Lee A, Rogers W, et al. Health-related quality of life in patients served by the Department of Veterans Affairs: results from the veterans health study. Arch Intern Med 1998 Mar 23;158(6):626-632. [doi: 10.1001/archinte.158.6.626] [Medline: 9521227]
25. Bruyère SM, Peterson DB. Introduction to the special section on the international classification of functioning, disability and health: implications for rehabilitation psychology. Rehabil Psychol 2005;50(2):103-104. [doi: 10.1037/0090-5550.50.2.103]
26. Bruyère SM, van Looy SA, Peterson DB. The international classification of functioning, disability and health: contemporary literature overview. Rehabil Psychol 2005;50(2):113-121. [doi: 10.1037/0090-5550.50.2.113]
27. de Groot S, Haisma JA, Post MW, van Asbeck FW, van der Woude LH. Investigation of bias due to loss of participants in a Dutch multicentre prospective spinal cord injury cohort study. J Rehabil Med 2009 Apr;41(5):382-389 [FREE Full text] [doi: 10.2340/16501977-0346] [Medline: 19363573]
28. Peterson DB. International classification of functioning, disability and health: an introduction for rehabilitation psychologists. Rehabil Psychol 2005;50(2):105-112. [doi: 10.1037/0090-5550.50.2.105]
29. Peterson DB, Rosenthal DA. The international classification of functioning, disability and health (ICF): a primer for rehabilitation educators. Rehabil Psychol 2005;19(2-3):81-94 [FREE Full text]
30. Israel BA, Eng E, Shulz AJ, Parker EA, Satcher D. Methods in Community-Based Participatory Research for Health. San Francisco, CA: Jossey-Bass; Oct 2012.
31. Mintz S. Caregiver disorder: an unacknowledged illness. Take Care 1996;5:1-10.
32. Nosek MA. Personal assistance: key to employability of persons with physical disabilities. J Appl Rehabil Couns 1990 Dec 1;21(4):3-8. [doi: 10.1891/0047-2220.21.4.3]
33. Decker SD, Schultz R, Wood D. Determinants of well-being in primary caregivers of spinal cord injured persons. Rehabil Nurs 1989;14(1):6-8. [doi: 10.1002/j.2048-7940.1989.tb00664.x] [Medline: 2911699]
34. Morgan DL. Focus Groups as Qualitative Research. Thousand Oaks, CA: Sage Publications; 1997.
35. Guest G, Bunce A, Johnson L. How many interviews are enough? Field Methods 2016 Jul 21;18(1):59-82. [doi: 10.1177/1525822X05279903]
36. Onwuegbuzie AJ, Collins KM. A typology of mixed methods sampling design in social science research. Qual Rep 2007;12(2):281-316 [FREE Full text]
37. Patton MQ. Qualitative Research & Evaluation Methods. Thousand Oaks, CA: Sage Publications; 2014.
38. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and implementing a triangulation protocol for qualitative health research. Qual Health Res 2006 Mar;16(3):377-394. [doi: 10.1177/1049732305285708] [Medline: 16449687]

Abbreviations

CAB: community advisory board
ICF: International Classification of Functioning, Disability, and Health
IRB: institutional review board
NNJSCIS: Northern New Jersey Spinal Cord Injury System
NSCID: National Spinal Cord Injury Database
PI: principal investigator
PTSD: posttraumatic stress disorder
QOL: quality of life
RC: research coordinator
SCI: spinal cord injury
SCIMS: Spinal Cord Injury Model System
VA: Department of Veterans Affairs
VANJHCS: East Orange Campus of the Veterans Affairs New Jersey Health Care System
VA SCI/D: Department of Veterans Affairs Spinal Cord Injury and Disorders
VBA: Veterans Benefits Administration
VHA: Veterans Health Administration

Edited by G Eysenbach; submitted 16.03.19; peer-reviewed by B Dixon, CH Cheng; comments to author 13.07.19; revised version received 26.07.19; accepted 28.07.19; published 04.10.19

Please cite as:
Fyffe DC, Williams J, Tobin P, Gibson-Gill C
Spinal Cord Injury Veterans' Disability Benefits, Outcomes, and Health Care Utilization Patterns: Protocol for a Qualitative Study
JMIR Res Protoc 2019;8(10):e14039
URL: https://www.researchprotocols.org/2019/10/e14039
doi: 10.2196/14039
PMID: 31588906

Best of Both Worlds: Establishing fruitful partnerships between VA SCI/D and SCI Model Systems Centers

Denise Fyffe, PhD
Kessler Foundation
Carol Gibson-Gill, MD & Joyce Williams, LCSW
Spinal Cord Injury/Disorders Service
Veterans Affairs New Jersey Health Care System

SCI Grand Rounds
October 24, 2019

KESSLER FOUNDATION

DEPARTMENT OF VETERANS AFFAIRS
New Jersey Health Care System

Disclosures

- None of the authors have any conflicts of interest to disclose.

Acknowledgements

CDMRP

Office of the Assistant Secretary of Defense for Health Affairs through the Spinal Cord Injury Research Program under Award No. W81XWH-17-1-0696

NiDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

Northern New Jersey SCI System
PIs: Trevor Dyson-Hudson, MD; Steven Kirshblum, MD
(NIDILRR Grant No: 90SI5011)

VA | U.S. Department of Veterans Affairs

Spinal Cord Injury Model System
SCIMS | NIDILRR
A NIDILRR Funded Program

Research Team

- Denise Fyffe, PhD (PI) – KF
- Carol Gibson-Gill, MD (Co-Investigator) – VANJHCS
- Joyce Williams, LCSW (Co-Investigator) – VANJHCS
- Ashleigh Quinn (Study Coordinator) – KF
- Yasheca Ebanks (Study Coordinator) – VANJHCS

Objectives

1. Describe the reasons Veterans seek their SCI care from VA SCI/D, SCIMS or both systems of healthcare.

2. Describe SCI clinicians' perspectives about coordinating rehabilitative care services across VA SCI/D and SCIMS settings.

3. Identify recommendations to improve collaboration in healthcare delivery across these two sites.

Background

- SCI was a common combat-related injury in the World Wars and Vietnam era
- SCI now affects more than 11% of military personnel injured in Operation Iraqi Freedom and Operation Enduring Freedom.
- Approximately 10 to 15% of Veterans sustain a SCI after military service.

The primary goals of SCI rehabilitation are to restore function, reduce secondary complications, and promote the health and sustainability of functional independence to maximize quality of life (QOL) after injury.

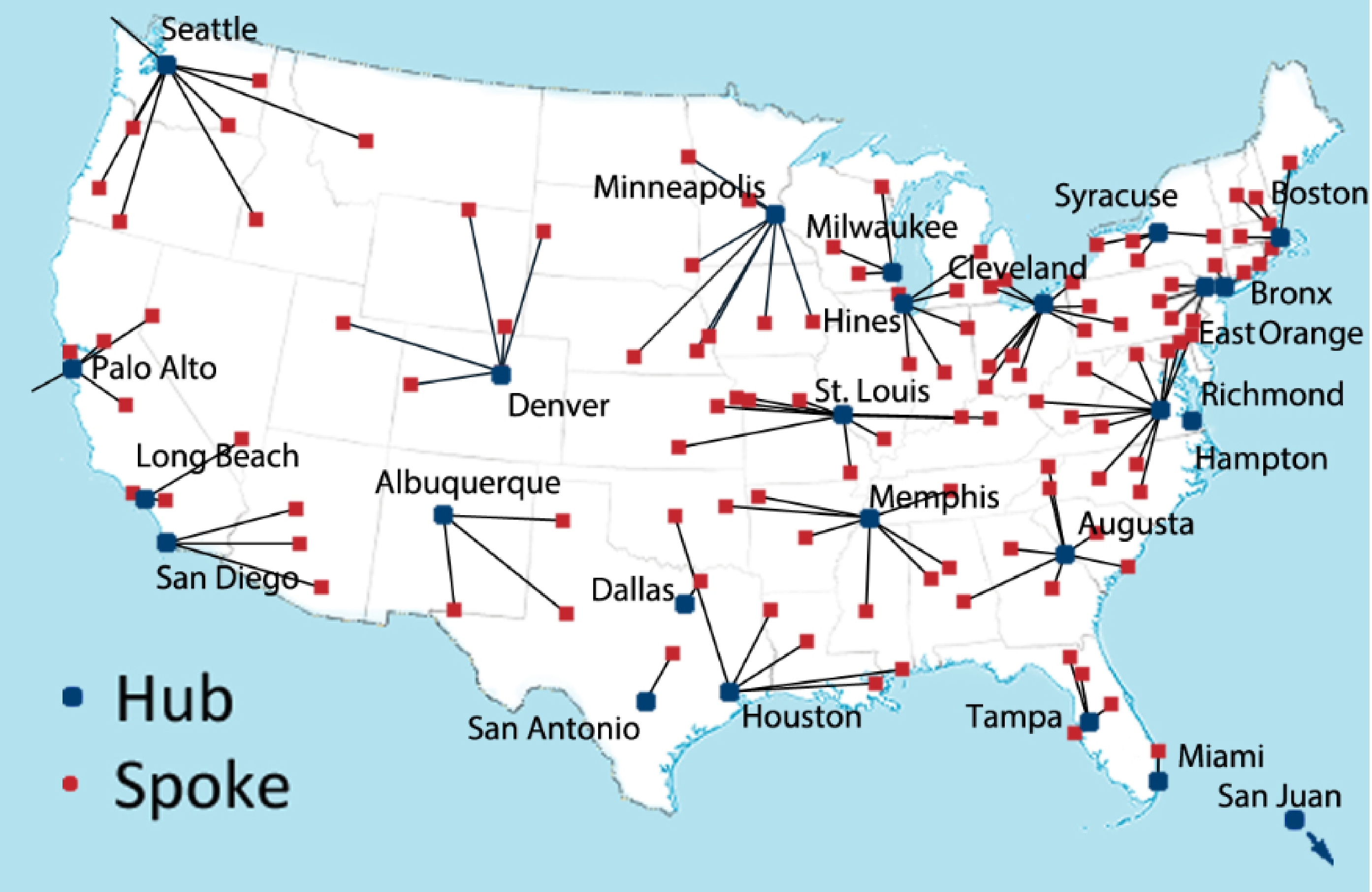
Gaps in SCI Healthcare

- Cost of living with an SCI
  - Secondary complications
  - Medical supplies
  - Home modifications
  - Mobility devices
- Caregiver burden
- Access to SCI care
- Coordination of care between private sector and Veterans Health Administration (VHA)

VA SCI/D Centers

- Veteran Health Administration (VHA) is the single largest SCI comprehensive health care provider in the nation.
- Approximately 42,000 Veterans with SCI are eligible to receive care at the VA health care facilities.

VA's Spinal Cord Injuries and Disorders System of Care



However…

- There are also an unknown number of Veterans who sustained an SCI following military service that have never used the VHA but are eligible to receive health care from the VHA.

Opportunities for improvement in SCI healthcare delivery to people living with SCI

SCIMS + VA SCI/D + X = 100%

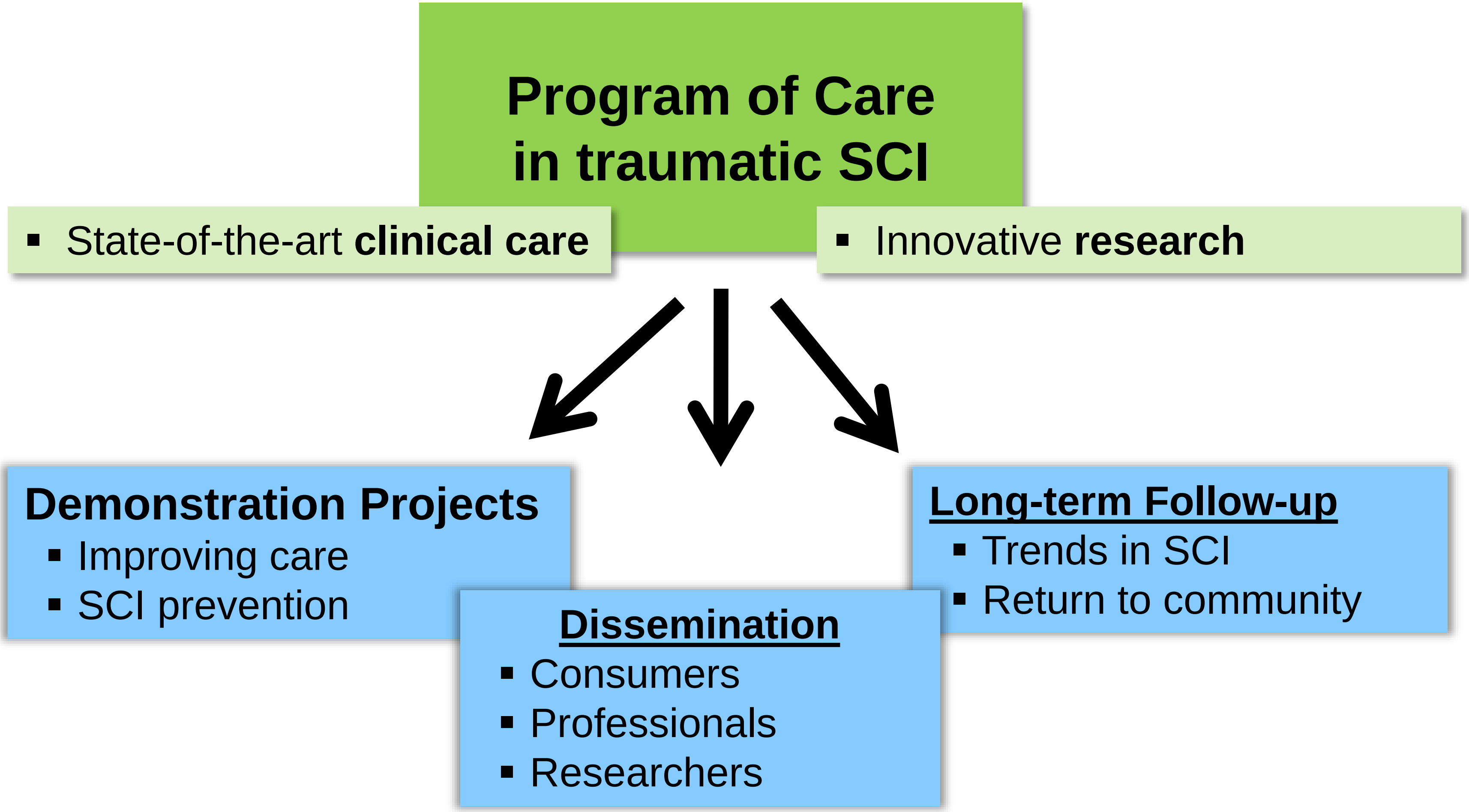
Spinal Cord Injury Model Systems (SCIMS)

Spinal Cord Injury Model System

SCIMS | NIDRR

A NIDRR Funded Program

SCIMS:
A “Model System”



Program of Care in traumatic SCI

- State-of-the-art **clinical care**
- Innovative **research**

Demonstration Projects
- Improving care
- SCI prevention

<u>Dissemination</u>
- Consumers
- Professionals
- Researchers

<u>Long-term Follow-up</u>
- Trends in SCI
- Return to community

Veterans Use of Healthcare Systems for SCI Care

- Some Veterans obtain their healthcare care exclusively through the VA SCI/D Centers or SCIMS Centers (i.e., single healthcare system users).

- Veterans with SCI may seek SCI care from both VA and private sector SCI centers (i.e., dual healthcare system users);

However…

- The reasons why some SCI Veterans prefer to seek their SCI care from one setting or both are not well understood
- Dual use increases the need to coordinate SCI clinical care across VA and SCIMS Centers…which needs further exploration.

Research Question

- What are Veterans reasons for seeking their SCI-care from VA, SCIMS or both healthcare systems?
- What are SCI Clinicians perspectives about the best way to coordinate care across VA and SCIMS systems of care?

Interviews with Veterans

Table 1. SCI Veterans	**Total** **N=69 (100%)**
Sociodemographic Characteristics	
Age (Mean ± SD)	59.5 ± 14.8
Non-Hispanic White (%)	42 (60.9)
Married (%)	36 (52.2)
Education: Some college	55 (79.7)
Household income ($25000 - $49000)	17 (26.5)
Spinal Cord Injury Status	
Mean years injured	15.0 ± 13.0
Injured after military duty	52 (75.3)
Paraplegia	31 (57.4)
Veteran History	
Branch: Army	27 (39.1)
Tour of duty: Vietnam (1964-1975)	22 (31.9)
Rank: E1 – E4	43 (63.1)

Primary Source of Healthcare

	n = 69	**%**
VA	36	52.17
SCIMS (private sector)	15	21.74
Dual Users (VA + private sector	18	26.09

Reasons for Veterans Choice of Healthcare Setting

1. misperceptions about VA healthcare eligibility, particularly when they have private insurance
2. lack of information about VA services and resources
3. lack of coordination of clinical care between VA and private sector SCI healthcare.

Veterans who primarily use VA for their healthcare (Sample Responses)

“I would say they [the VA] give me a higher priority. I used to call my family doctor to, you know, maybe complain about an illness or something, and they would want to schedule me three or four months down the road or just tell me to go to the emergency room. I feel like if I call the VA right now and tell them I have an issue, they're going to want to know how quick I can get there. Correct. I did not see that in the private sector at all. No, I-I-I think just the timeliness is the only thing I really think.”

“…because of my injury, I do get Medicaid or Medicare. I get, you know, 100% Medicare taken, so really I, I mean, the option is there for me to use the outside, uh, uh, health care system. The only thing is, I feel-- I actually feel more comfortable using the VA, because of my-- they have my life history, and they, you know, they've been working on it, and they understand me better. And I'm not crazy about going to 20 different doctors right now…At least right there in the VA hospital, if I have to go to them, they're all right there in the hospital. I'm not going all over fricking half the state of Jersey.”

“Um, anything on my wheelchair that breaks, I get uh-- you know like the VA pays for it—they— They also make [inaudible], stuff like that. They get hand controls on the car. And stuff like that. You know, anything, you know, for the home I need, they'll get me.”

Veterans who primarily use SCIMS for their healthcare (Sample Responses)

“Oh, I didn't. Honestly, it just never occurred to me…when I got of the service, right after I was discharged, I had my wisdom teeth pulled at the VA hospital… And that was-- that was the first and only time I've ever been in a VA hospital as a patient. I always had…very good… medical insurance…never, had any particular need to seek out medical assistance from the VA.”

“And then you know, what the problem was when I went to the VA doctor-- I gave them a list of all my medicines, and now, I have diabetes-- --and they, they pretty much told me that all the medicines on my list are not approved by the VA. And so the doctor started naming their, uh, medicines that they would give me and there was medicines that I have tried in the past-- --and was taken off of because they was doing damage to my liver…The VA doesn't do Crestor, they do Lipitor. I tried Lipitor, and that did-- one of the medicines that made-- that, you know, you do a blood test and it shows what the damage it does to your liver… So why would I go back to that?.”

“Well, it’s, it’s typical government. Too much red tape. To go through the motions of going and getting this and that. [private] I have to call my doc up, "Hey, doc." “Okay. Be there at 3:00…With them, you have-- you call the VA. You have to make an appointment. "Well, we'll see if this doc is going to be available on this date." “Well, yeah, but that's the date that I have—“ “Well, that's the only time the doctor's going to be in, so.” Next time, it might be six months from now before-- if you're sick, you're sick. Sick today. You're dead six months from now. You know? Nobody looked at me..”

SCI Clinician Focus Groups

Table 1. SCI Clinicians	**Total N=19**	**VANJHCS n=9**	**Kessler N=10**
Demographics			
Female (%)	16 (84.2)	7 (43.7)	9 (56.2)
Age (Mean + SD)	46.5 ± 10.1	41.5 ± 9.7	51 ± 8.7
Non-Hispanic White (%)	10 (52.6)	2 (20.0)	8 (80.0)
Married (%)	12 (63.1)	5 (41.7)	7 (58.3)
Clinical Experience			
Physiatrist	2 (10.5)	1 (50.0)	1 (50.0)
Nurse	6 (31.6)	3 (50.0)	3 (50.0)
Therapist (PT/OT/RT)	4 (21.0)	2 (50.0)	2 (50.0)
Psychologist/Social Worker	4 (21.0)	2 (50.0)	2 (50.0)
Case Manager	2 (10.5)	0 (0)	2 (100.0)
Nutritionist	1 (5.3)	1 (100.0)	0 (0)
Number of years practicing in current position	11.5 ± 8.8	9.3 ± 9.1	13.4 ± 8.5
Number of years working with SCI Veterans	14.9 ± 17.2	6.4 ± 4.4	22.6 ± 21.0

SCI Clinician Quotes

SCIMS

- “We don’t have a good system for tracking Veterans”
- “There’s more available to our VA pts that wouldn’t be available to other people.”
- “For some vets, there’s an inherent belief that the VA is not as good as private insurance”
- “family has to be on board”

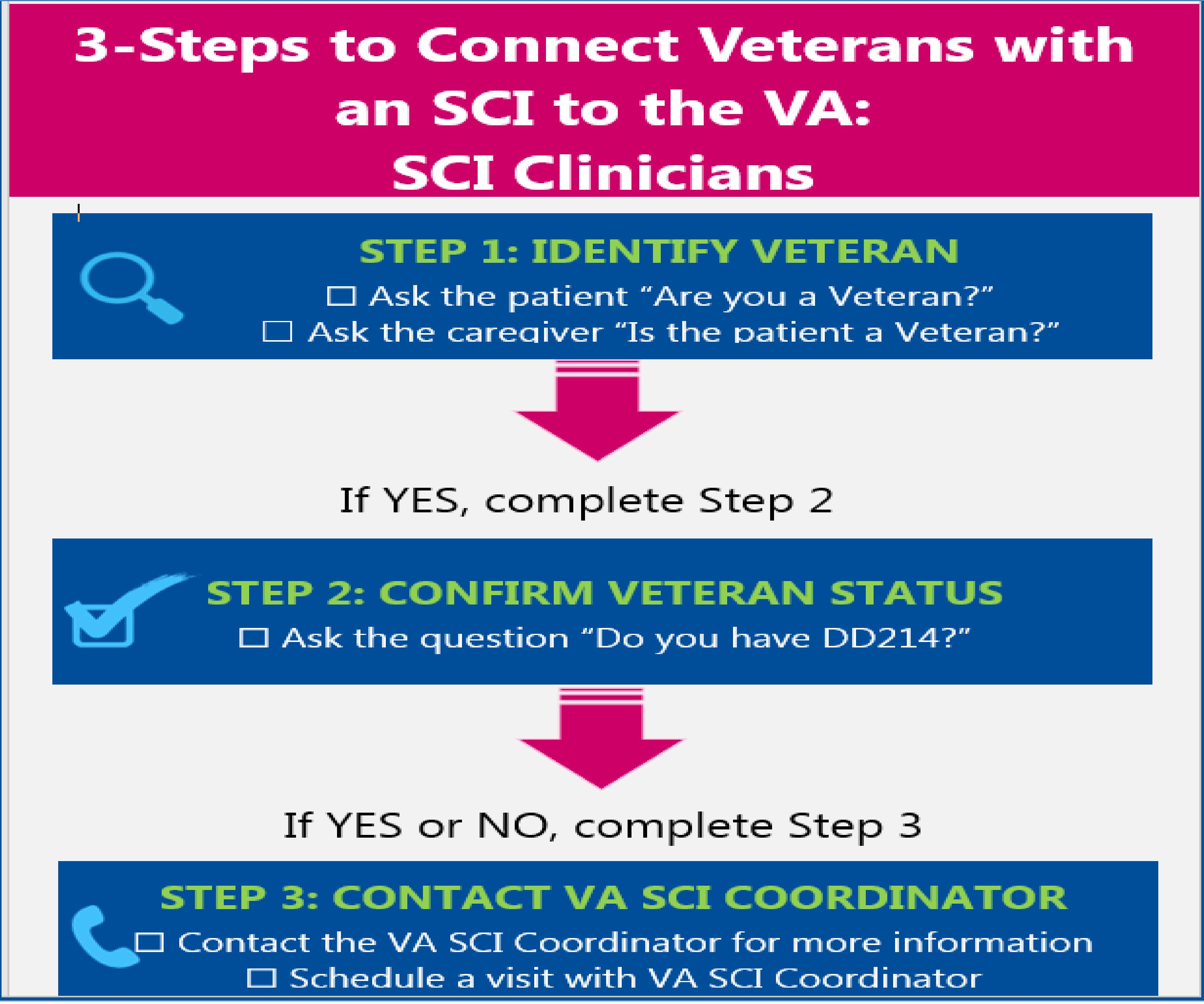
VANJHCS

- “civilian has a shorter time frame to work with Veteran they are more focused on…and VA seems to be an afterthought”
- “letting Veterans know that they can get care across both sites”
- “reputation of the VA needs to be improved”
- “Having a contact person”

Best of Both Worlds: VA SCI Center & SCIMS Collaborative Care Model

Admission

- Identify and document that a patient is a Veteran (e.g., new eMR).
- Notify VA SCI Coordinator about potential patient upon admission or early in their acute stay



3-Steps to Connect Veterans with an SCI to the VA: SCI Clinicians

STEP 1: IDENTIFY VETERAN

☐ Ask the patient “Are you a Veteran?”
☐ Ask the caregiver “Is the patient a Veteran?”

If YES, complete Step 2

STEP 2: CONFIRM VETERAN STATUS

☐ Ask the question “Do you have DD214?”

If YES or NO, complete Step 3

STEP 3: CONTACT VA SCI COORDINATOR

☐ Contact the VA SCI Coordinator for more information
☐ Schedule a visit with VA SCI Coordinator

During Rehabilitation

- Initiate the enrollment of non-enrolled into the VHA system (e.g, getting their forms sorted out: DD214)

- Partnership/ Demystifying the VA (Meet & Greet)

- Addressing discharge/clinical needs

Discharge Planning

- Improving key elements of discharge planning
  - home evaluation before the SCI Veteran is discharge
  - home modifications
  - equipment needs to prepare the SCI Veteran and their family for life at home.

- Reducing gaps in the continuum of care by the SCI Coordinator

Best of Both Worlds from the Voices of our Veterans (Dual Users)

"Insurance had me leave SCIMS and, uh, believe me, I was-- I was simply not ready to leave…the VA put me up for another month… *I think there should be something on there where, if you're a veteran and you're taken into SCIMS, something immediately and automatically alerts you to the VA. And so [VA staff] can come out there and interview you…*that's, that's my, my only beef--because I would have gone home with absolutely nothing. I would have gone home with this big ass clunker of a wheelchair that would have been a loaner from, uh, SCIMS--until after a month or two, I would have gotten my aluminum chair, which is not titanium, which I would have been happy with. And I would have not had all the follow-up benefits, like staying at the VA for a month, even though I wasn't ready to go home."

"…the aftercare looks like, you know, how people come through SCIMS and, you know, like stand up, and do all these exercises every day. But the VA…didn't provide *that…There was like some things I missed out on when I went to the VA, but the VA also did do a lot for me, in the same token.* Like I never-- like I didn't do my outpatient because I was-- I was inpatient. I went from SCIMS to the VA. -- then the VA didn't provide, um, um-- what was that? Aftercare. But what the VA did do for me was like, wheelchairs, like manual, power. The military gave me so much stuff, it was crazy. And I'm like, "Wow." I felt like I was a kid being blessed, like, for Christmas or something."

3-Steps to Connect Veterans with an SCI to the VA: SCI Clinicians

STEP 1: IDENTIFY VETERAN

☐ Ask the patient "Are you a Veteran?"

☐ Ask the caregiver "Is the patient a Veteran?"

If YES, complete Step 2

STEP 2: CONFIRM VETERAN STATUS

☐ Ask the question "Do you have DD214?"

If YES or NO, complete Step 3

STEP 3: CONTACT VA SCI COORDINATOR

☐ Contact the VA SCI Coordinator: (973) 676-1000 (x 1729)

☐ Schedule a visit with VA SCI Coordinator