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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
East Hanover, NJ 07936

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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 Year 3, the research team worked with the Community Advisory Board (CAB) to complete numerous administrative tasks required to implement study procedures, data collection and review data summaries. Administrative tasks that are ongoing include maintenance of IRB approval for continuation and amendment across both sites (Kessler and VANJHCS) as well as HRPO approval.

A summary of Year 3 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. Data cleaning and analyses are ongoing.

Phase II: Semi-structured interviews continue across both sites. At Kessler, 26 out of 30 participants enrolled and completed interviews. At VANJHCS, 20 out of 30 participants enrolled, and 15 out of 30 completed interviews.

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. Data cleaning and analyses are ongoing.

The implementation of Phase 5 is pending the triangulation of data across Phases 1-4, which will take place in year 4 of the study.

15. SUBJECT TERMS

SCI Veterans, socioeconomic factors, VA disability compensation and benefits

16. SECURITY CLASSIFICATION OF:			**17. LIMITATION OF ABSTRACT**	**18. NUMBER OF PAGES**	**19a. NAME OF RESPONSIBLE PERSON**
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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	Ongoing
Coordinate with Sites for Kessler IRB protocol submission	1-3	KF/ VANJHCS	Ongoing
Coordinate with Sites for Military 2nd level IRB review (ORP/HRPO)	1-6	KF/ VANJHCS	Ongoing
Submit amendments, adverse events and protocol deviations as needed	As needed	KF/ VANJHCS	Ongoing
Coordinate with Sites for annual IRB report for continuing review	Annually	KF/ VANJHCS	Ongoing
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	KF/ VANJHCS	100%
Coordinate with research staff training	As needed	KF/ VANJHCS	Ongoing
Milestone Achieved: Research staff trained	As needed	KF/ VANJHCS	Ongoing
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	80%
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	25%
Milestone Achieved: Phase II of study completed	22-26	KF/ VANJHCS	25%
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	1000%
QSR Consultation: Coding (caregiver and clinician focus groups) planning and periodic review, including inter-coder consistency	27-30	KF/ VANJHCS	25%
Milestone Achieved: Report findings from family caregiver interviews/focus groups and SCI clinician focus groups	27-30	KF/ VANJHCS	25%

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	Initial submissions complete; amendments submitted as needed
Submit amendments, adverse events and protocol deviations as needed	As needed	Ongoing amendments, adverse events, and deviations all reported in year 3
Coordinate with Sites for annual IRB report for continuing review	Annually	As requested by respective IRB offices and HRPO
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	Completed
Coordinate research staff training	As needed	Ongoing – required for each phase of the project to maintain adequate data quality and WOC status
Milestone Achieved: Research staff trained	As needed	Ongoing - required for each phase of the project to maintain adequate data quality and WOC status
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)*	Ongoing	Recruitment is ongoing in Phase II: - 26 out of 30 participants enrolled and completed interviews at KF - 20 out of 30 participants enrolled, and 15 out of 30 completed interviews at VANJHCS
Monthly progress reports to CAB	3-30	Ongoing
QSR Consultation: Coding (chart review and interviews) planning and review, including inter-coder consistency	24-28	Data management planning was initiated during latest consultation for Phase II
Milestone Achieved: Phase II of study completed	22-26	Pending completion of data collection, cleaning and analyses
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	Data management planning was initiated for the focus group data during last consultation
QSR Consultation: Data collection and transcription planning (clinician focus groups)	24-27	Data management planning was initiated for the focus group data during last consultation
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:

Based on the SOW, we completed portions of Major Task 2 – Subtask 1; however, we did not meet the goals listed for Major Task 2 – Subtask 2: complete semi-structured interviews with service-connected and non-service connected SCI Veterans. The goals listed for Subtask 2 are dependent on the outcomes of Subtask 1.

Phase I: Procurement of the medical records was challenged by limited administrative access to medical records at Kessler and transition to electronic medical records. Medical record abstraction is complete at KF and VANJHCS. Iterative data cleaning and analyses are ongoing.

Phase II: Delays in initiating recruitment at VANJHCS was due to the findings of the first consent audit, and resolving the issues about 1) obtaining consent for participants with impaired upper limb functioning (i.e., tetraplegia) and 2) the protocol including IRB approved HIPAA Waivers of authorizations and HIPAA authorizations. A consent audit was conducted on 12/4/2018, the full regulatory audit was on 02/12/2018. The study team met with the IRB chair, IRB coordinator, PO, and investigators) to resolve the HIPAA issues was 02/23/2018. The requested changes to the protocol about these issues (which was requested to go through IRB review) was submitted on 04/10/2018 and approved 05/11/2018.

Data Quality Management and Analyses: Transcription of the semi-structured interviews was delayed by the process of procurement of transcription vendors at both sites. Transcription services rendered from TranscribeMe! For Kessler Foundation continue for Phase II. Alternate transcription services are being secured at VANJHCS.

Study Equipment Logistic Problems at VANJHCS: As collection began at VANJHCS, we were notified of a recent change in the Federal and Department security and privacy policies and guidelines. The digital recorders that we planned to use at the VANJHCS must be advanced encryption standard (AES)-256 compatible in order to be in accordance with revised Federal and Department security and privacy policies and guidelines for VA technologies. A Philips DPM8000 digital audio recorder was purchased and used for data collection at VANJHCS. The research team coordinated with VANJHCS officers to facilitate uploading data from the digital audio recorder to the approved, secure network drive location via the VA furnished laptop for analyses. It took approximately 140 days to obtain the required signatures from VANJHCS IT staff and officers to approve the downloading of the narrative data from the VA-approved audio recorder to the study drive via the laptop.

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.

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.

The primary goal of next reporting period is to complete data collection and thereby accomplish the goals listed for Major Task 2. Managing data quality is another key goal as data collection continues as the research team prepares for the analyses of data for each phase of the study. The SOW was revised to reflect the anticipated timeline changes. An updated version of the SOW is included in the Appendix 1.

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	Ongoing	
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	27-48	Ongoing	

periodic review, including inter-coder consistency			
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	DF	CG
Conduct qualitative data analyses (triangulate qualitative data)	37-48	DF	CG
Develop practices and policy recommendations with CAB	24-48	DF	CG
Conduct evaluation focus groups *(N=20; 10 participants per site)*	40-44	DF	CG
QSR Consultation: Coding (evaluation focus groups) planning and periodic review, including inter-coder consistency	40-44	DF	CG
QSR Consultation: Review of coding, triangulation of data sources, strategies for identifying other key patterns and findings for dissemination efforts	37-48	DF	CG
Work with research team and CAB to disseminate findings at national professional meetings (e.g., abstracts, presentation, publications)	37-48	DF	CG
Milestone Achieved: Practice & Policy Recommendations Reports generated from study findings	37-48	DF	CG

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.

Based on SCI clinician's from both sites participating in focus groups the following interdisciplinary recommendations were made to facilitate coordination of care across 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.

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.

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.

(a) *Protocol Changes for Phase I (02/10/2017):*

Recruitment Goals: Due to recruitment challenges, which included ineligibility due to non-traumatic SCI and dated medical charts, we revised our recruitment goals. The PI obtained approval to recruit/enroll up to 25 participants at each site for the chart review. IRB amendments were approved at both sites.

(b) *Protocol Changes for Phase II (06/07/2017):*

Inclusion/Exclusion Criteria: Based on preliminary findings from Phase I and to facilitate the recruitment goals of Phase II, the PI requested a modification of the inclusion criteria. The PI corresponded with her program officer to consider extending the inclusion criteria for this phase of the study to include veterans with non-traumatic SCI at both sites. The PI received approval for this change in our approach on 06/07/2017.

Delays in initiating recruitment at VANJHCS was due to the findings of the first consent audit, and resolving the issues about 1) obtaining consent for participants with impaired upper limb functioning (i.e., tetraplegia) and 2) the protocol including IRB approved HIPAA Waivers of authorizations and HIPAA authorizations. A consent audit was conducted on 12/4/2018, the full regulatory audit was on 02/12/2018. The study team met with the IRB chair, IRB coordinator, PO, and investigators) to resolve the HIPAA issues was 02/23/2018. The requested changes to the protocol about these issues (which was requested to go through IRB review) was submitted on 04/10/2018 and approved 05/11/2018.

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.

a. *Recruitment delays:* Based on preliminary findings from Phase I and to facilitate the recruitment goals of Phase II the PI requested a modification of the inclusion criteria. The PI corresponded with her program officer to consider extending the inclusion criteria for this phase of the study to include veterans with non-traumatic SCI at both sites. The PI received approval for this change in our approach on 06/07/2017. Delays in initiating recruitment at VANJHCS was due to the findings of the first consent audit, and resolving the issues about 1) obtaining consent for participants with impaired upper limb functioning (i.e., tetraplegia) and 2) the protocol including IRB approved HIPAA Waivers of authorizations and HIPAA authorizations. A consent audit was conducted on 12/4/2018, the full regulatory audit was on 02/12/2018. The study team met with the IRB chair, IRB coordinator, PO, and investigators) to resolve the HIPAA issues was 02/23/2018. The requested changes to the protocol about these issues (which was requested to go through IRB review) was submitted on 04/10/2018 and approved 05/11/2018.

b. Staffing Changes. The following staff changes took place over the past year to assist with completion of the project: Rukshana Jalil was hired and started her employment at Kessler Foundation on July 16, 2018.

c. Logistical delays with IT and purchasing. Final approval to order the VA laptop was confirmed with the VANJHCS the Veterans Bio-Medical Research Institute and Kessler on 08/17/2016. A laptop was purchased, tagged by VA logistics on 02/16/2017, imaged by VA IT department who also uploaded the data analytic software, and delivered to the PI by 04/15/2017.

d. *Transcription Services:* Transcription of the semi-structured interviews was delayed by the process of procurement of transcription vendors at both sites. TranscribeME! was secured as a transcription service at KF. However, a problem with the data quality in the transcription of 10 semi-structured interviews from Phase II from TranscribeMe! This problem led to multiple reviews and revisions of these 10 transcripts from the research staff and unfortunately increased the workload in managing the data. The PI has worked out a resolution with TranscribeMe! to increase the likelihood of them producing a better quality transcript. The research team the KF will continue receiving transcripts for Phase II from TranscribeMe!

At VANJHCS, the PI is negotiating with VA Salt Lake City (VASLC), Centralized Transcription Services Program was terminated. The PI is negotiating the procurement of KeyStrokes. DUA's were drafted and are being reviewed by VANJHCS officers: VA Information Security Officer and VA Privacy Officer.

e. *Plans for resolution of delays*. We will make every effort to conduct activities moving forward as in the timeframe proposed in the original statement of work. Staffing changes should facilitate the completion of required deliverables. An "Extension without Funds" was approved on and a revised SOW is included to

account for the delays and an updated timeline has been proposed for extension year of the project (see Appendix).

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.

In anticipation of the recruitment and data management demands of the project, the PI redistributed the allocation of staff effort and responsibilities across the Research Coordinator and 2 Research Assistants.

With much of the administrative tasks required to launch the study and initiate the IRB process completed, the study coordinator, Ashleigh Quinn, will be reduced to 50% FTE (6 (calendar year - CY) person months and focus her efforts on completing recruitment and enrollment for Phase II and III at the VANJHCS.

The PI with utilize the salary difference to hire 2 half-time Research Assistants to manage the recruitment/enrollment needs of the study at Kessler (i.e., due to time constraints the Research Assistants will not be seeking WOC status at the VANJHCS):
1. Armani Wynn was hired as a Research Assistant at on July 5, 2017 at 50% FTE (6 CY- person months).
2. Rukshana Jalil was hired as a Research Assistant on July 16, 2018 at 50% FTE (6 CY- person months).

The cumulative effect of the aforementioned administrative, recruitment, data collection and management delays lead to the submission of an extension without funding. A fully executed subject modification was received on 05/24/18 extending the contract to 07/29/18.

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.

Significant changes in use or care of human subjects

Phase I: Our recruitment efforts were stymied by two barriers: 1) an inability to access dated medical records of older SCI Veterans (particularly at Kessler); and 2) eligibility criteria did not include non-traumatic SCI Veterans. We ascertained that we would have to revise our recruitment strategy in order to obtain a sufficient number of participants with complete medical records at both sites. On 03/31/2017, the PI submitted a request to the Scientific Officer to increase the number of participants recruited to 25 to increase the likelihood of reaching our recruitment goal of 15 medical records. Request by the Scientific Officer was granted on 04/17/2017. An IRB amendment was submitted and approved at both sites. On

06/22/2017 recruitment and enrollment was completed for Phase I and included 17 SCI Veterans at Kessler and 15 at the VANJHCS. Procurement of the medical records has been challenged by limited administrative access to medical records at Kessler. Medical record abstraction is ongoing at VANJHCS. Iterative data cleaning and analyses are ongoing.

Phase II: Based on the small sample of SCI veterans who are service connected in Phase I (31.3%) and high proportion of ineligible participants (n=6), we revised inclusion criteria for Phase II. The PI submitted a change request to her Scientific Officer to extend the inclusion criteria for this phase of the study to include veterans with non-traumatic SCI at both sites. The PI received approval for this change in our approach on 06/07/2017. This amendment to the IRB protocol was approved at KF and VANJHCS. To address these challenges, we implemented a consecutive data collection strategy across both sites.

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 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.

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).

- **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 Dr. Fyffe with the training procedures for Armani Wynn.

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.

In anticipation of the recruitment demands of Major Task 2, the PI will redistribute the allocation of staff effort and responsibilities across the Research Coordinator and 2 Research Assistants.

With much of the administrative tasks required to launch the study and initiate the IRB process completed, the study coordinator, Ashleigh Quinn, will be reduced to 50% FTE (6 (calendar year - CY) person months and focus her efforts on completing recruitment and enrollment for Phase II and III at the VANJHCS.

The PI with utilize the salary difference to hire 2 half-time Research Assistants to manage the recruitment/enrollment needs of the study at Kessler (i.e., due to time constraints the Research Assistants will not be seeking WOC status at the VANJHCS):
1. Armani Wynn was hired on July 5, 2017 at 50% FTE (6 CY- person months).
2. The PI hired a new Research Assistant, Rukshana Jalil on 07/16/2018 (50% FTE; 6 CY- person months).

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: Publication
d. Appendix 4: PVA Summit poster presentation abstract

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	DF	CG
Coordinate with Sites for annual IRB report for continuing review	Annually	DF	CG
Milestone Achieved: Local IRB approval at Kessler and EOVA	3	Complete	
Coordinate with research staff training	8-11	Ongoing	
Milestone Achieved: Research staff trained	8-12	Ongoing	
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	Ongoing	
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	DF	CG
Conduct qualitative data analyses (triangulate qualitative data)	37-48	DF	CG
Develop practices and policy recommendations with CAB	24-48	DF	CG
Conduct evaluation focus groups *(N=20; 10 participants per site)*	40-44	DF	CG
QSR Consultation: Coding (evaluation focus groups) planning and periodic review, including inter-coder consistency	40-44	DF	CG
QSR Consultation: Review of coding, triangulation of data sources, strategies for identifying other key patterns and findings for dissemination efforts	37-48	DF	CG
Work with research team and CAB to disseminate findings at national professional meetings (e.g., abstracts, presentation, publications)	37-48	DF	CG
Milestone Achieved: Practice & Policy Recommendations Reports generated from study findings	37-48	DF	CG

<table>
<tr><th></th><th>Yr 1</th><th>Yr 2</th><th>Yr 3</th><th>EWOF</th></tr>
<tr><td>Q1</td><td></td><td></td><td rowspan="4">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)</td><td rowspan="4">In-depth interviews: 30 service connected
and 30 non-service connected veterans

Evaluation focus groups (N=20; 10 participants per site)</td></tr>
<tr><td>Q2</td><td></td><td rowspan="3">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)</td></tr>
<tr><td>Q3</td><td rowspan="2">Chart Review: 15 charts reviewed per site</td></tr>
<tr><td>Q4</td></tr>
</table>

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

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

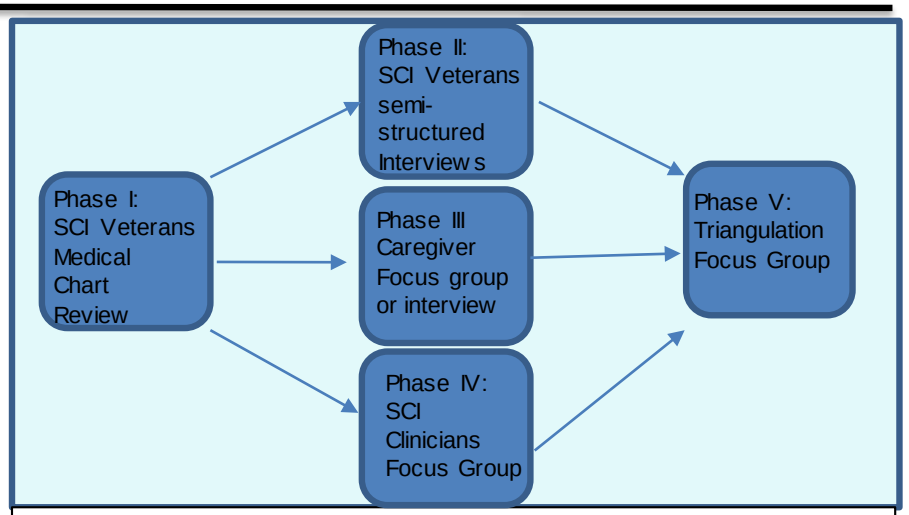
PI: Denise Fyffe, PhD **Org:** Kessler Foundation **Award Amount:** $598,000.00

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.



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)	100223.50	198278.50	198776.50	100721.50

Updated: 8/29/2018

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, analysis and dissemination
- ☐ Complete data collection, data cleaning, analysis and dissemination

Comments/Challenges/Issues/Concerns
- Timelines change due to administrative issues (e.g., WOC clearance process), staff changes, IRB delays, VA equipment purchases.

Budget Expenditure to Date

Projected Expenditure:: $598,000.00

Actual Expenditure $409,488.00

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Late-Breaking Research Posters

Late-Breaking Research Poster 314866

RCT of Peer-Led Phone-Based Empowerment Intervention for Persons with Chronic Spinal Cord Injury Improves Health Self-Management

Bethlyn Houlihan (Spaulding New England Regional SCI Center, Boston Univ School of Public Health), Miriam Brody, Sarah Skeels, Diana Pernigotti, Judi Zazula, Sam Burnett, Christa Green, Subramani Seetharama, Stathis Hasiotis, Timothy Belliveau, David Rosenblum, Alan Jette

Research Objectives: Evaluate the impact of "My Care My Call", a novel telephone-based, peer-led self-management empowerment intervention in adults with chronic spinal cord injury (SCI).
Design: Randomized controlled trial.
Setting: General community.
Participants: Convenience sample of 84 adults with SCI 1+ years post injury with telephone access endorsing an unmet health need. Thirty seven had paraplegia, 47 tetraplegia; 62 male; 49 White, 21 African American, 10 Hispanic, 4 Other; 18-78 years-old.
Interventions: Peer Health Coaches (PHC) applied person-centered goal-setting support, motivation, education, and referral with experimental subjects (n=42) over 6 months. The control group (n=42) received usual care.
Main Outcome Measures: Primary outcome: health self-management behavior (Patient Activation Measure -PAM); Secondary outcomes: Social/Role Activities Limitations, Global Ratings of Service/Resource Use, Health-Related Quality of Life (HRQOL), and Quality of Primary Care (Communication with Physicians Scale; Patient Satisfaction Scale).
Results: Intervention participants reported significantly greater change in PAM scores ($p=0.0468$) at 6 months compared to controls. The intervention group's PAM score increased an average of 7.029 points more from baseline to 6 months, than controls. PAM change scores were higher in the intervention vs. control group for individuals within the following subgroups: higher education level, high levels of social support, 1-6 years post-injury, tetraplegia, male, and white. At 6 months, intervention participants also reported a significantly greater decrease in social/role activities limitations; greater change in life satisfaction; greater services/resources awareness; greater overall service use; and a greater number of services used. We found no significant changes related to the Communication with Physicians or Patient Satisfaction Scales.
Conclusions: A novel telephone-based, peer-led empowerment intervention can achieve meaningful improvements in health self-management for adults with SCI, warranting a larger, multi-site trial including secondary conditions outcomes.
Key Words: Spinal Cord Injuries, Telemedicine, Peer Support
Disclosures: None disclosed.

Late-Breaking Research Poster 342476

Exploring Disability Compensation Among Veterans with Spinal Cord Injury

Denise Fyffe (Kessler Foundation/Rutgers-NJMS), Carol Gibson-Gill, Joyce Williams, Ashleigh Quinn

Research Objectives: To examine the factors associated with differential patterns of disability compensation among Veterans with SCI.
Design: This cross-sectional study used a mixed methods to gather data with open-ended questions and structured questionnaires, such as Survey of Retired Military and National Survey of Veterans. A retrospective chart review was also conducted.
Setting: Two study sites that serve SCI veterans in New Jersey area conducted the study: Veterans Administration New Jersey Healthcare System (VANJHCS) and Northern New Jersey Spinal Cord Injury System.
Participants: After obtaining IRB approval, a sample of 35 male Veterans with traumatic SCI from VANJHCS and/or SCI Model Systems patient registries were recruited to participate in the study.
Interventions: Not applicable.
Main Outcome Measures: Not applicable.
Results: Descriptive analyses indicate the mean age of participants was 60.2+16.3 years and median time post-injury was 15.3+16.3. While 61.1% of the participants had a non-service connected SCI, approximately one-third (38.9%) of participants were service-connected for SCI or another disability (e.g., PTSD). Approximately 69.6% of participants receive Social Security disability benefits; while 30.4% receive VA disability compensation benefits. Qualitative content review indicated 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 eligibility and coverage.
Conclusions: Preliminary findings suggest that a small proportion of participants receive VA disability compensation benefits. Participants' responses indicate that SCI Veterans 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. These findings underscore the need to improve SCI Veterans and their families' knowledge about disability compensation benefits and provide clinicians with an educational opportunity to facilitate access to these supportive resources.
Key Words: Spinal Cord Injury, Veterans Disability Claims, Health Status
Disclosures: None.

Late-Breaking Research Poster 342995

Differential Item Functioning on Physical Disability Measure Across Direct and Proxy Interview

Ickpyo Hong (University of Texas Medical Branch), Mi Jung Lee, Catherine Hay, Timothy Reistetter

Research Objectives: To examine the stability (direct vs. proxy interviews) of survey items assessing functional status by using item response theory (IRT).
Design: Secondary data analysis from a population-based survey of the 2012 U.S. Health and Retirement Study. A physical disability scale was created using the 10 activities of daily living and 12 physical function items based on the two IRT models. The psychometric properties of the physical disability measurement were tested using the Rasch model and 2-parameter (2-PL) IRT model. In addition, the stability of function items across the interview type (direct vs. proxy) was examined by differential

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

Authors: Denise Fyffe, PhD, Joyce Williams MSW, Carol Gibson-Gill, MD

Learning objectives:

1. Increase participants' knowledge about the aspects of rehabilitation services that overlap and vary across VA SCI/D Centers and SCI Model Systems (SCIMS) for SCI Veterans.

2. Participants will learn about SCI veterans and providers' perspectives about coordinating rehabilitative care services across VA SCI/D Centers and SCI Model Systems (SCIMS) settings.

3. Participants will learn strategies and benefits to improve the collaboration of rehabilitative care services across VA SCI/D Centers and SCI Model Systems (SCIMS) settings for SCI Veterans.

Background:
Spinal cord injury (SCI) is among the most devastating and disabling medical conditions affecting wounded service men. The Veterans Administration SCI/D System of Care, described as a "hub and spoke" system, includes 24 regional SCI/D Centers (known as "hubs") that provide a comprehensive range of inpatient care, rehabilitation, specialty care and coordinated lifelong continuum of care delivered by interdisciplinary teams. On the civilian side, the NIDILRR-sponsored SCIMS are specialized programs of SCI care that gather information and conduct research with the goals of improving health and function, employment, and community living and participation. While some SCI veterans obtain their rehabilitation care through the VA SCI/D Centers, others utilize civilian settings, like SCIMS Centers. Seeking care through both SCI systems may enhance access, flexibility and choice in rehabilitation care for Veterans; however, some veterans only utilize one system of care. The reasons why some SCI veterans prefer to seek rehabilitative care from one setting over another are not understood, nor have the implications of coordinating clinical care across VA and SCIMS Centers been explored.

Design: Cross-sectional study.

Methods: After obtaining IRB approval, purposeful sampling techniques were used to recruit 32 Veterans and 20 interdisciplinary SCI providers from the VA New Jersey Healthcare System (VANJHCS) SCI/D "Hub" Center and Northern New Jersey Spinal Cord Injury System (SCIMS). SCI Veterans completed semi-structured questionnaires and SCI providers participated in focus groups.

Results:
The majority of SCI Veterans recruited from the VA, primarily used the VA for their rehabilitative care. SCIMS participants primarily utilized services at the SCIMS and described three main barriers to care at the VA: 1) misperceptions about their eligibility for VA care, particularly when they have private insurance; 2) lack of information about and services available to them; and 3) lack of coordination across services. SCIMS providers explained the need to document SCI Veteran status at admission as useful to their care and discharge planning during acute rehabilitation. SCI providers across both sites concur that useful strategies to coordinate care include: 1) having a contact person on the interdisciplinary teams; 2) understanding logistics of length of stay; and 3) ongoing education and communication of SCI providers across sites. All

study participants were provided with educational material from VHA and Veterans Benefits Administration (VBA) as well as contact to SCI/D Coordinator at VANJHCS.

Conclusions:
Dual use of SCI rehabilitative care by SCI Veterans was not common in our sample. This may be related to the Veterans', families' and/or providers' lack of knowledge of all the VA benefits available. These findings underscore the need to devise effective ways to collaborate and provide education about these benefits across the spectrum of Veterans health care to DoD, VHA and SCIMS. SCI clinicians' perspectives indicate that the comprehensive nature of rehabilitative care requires interventions (e.g., documentation of veteran status) at multiple time-points during rehabilitative care in the SCIMS centers to facilitate their collaboration with the VA.