AWARD NUMBER: W81XWH-17-1-0262

TITLE: Triangle of Healthy Caregiving for Spinal Cord-Injured Veterans

PRINCIPAL INVESTIGATOR: Carol Gibson-Gill M.D.

CONTRACTING ORGANIZATION: Veterans Bio-medical Research Institute

East Orange, NJ 07018

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14. ABSTRACT

Spinal cord injury (SCI) is among the most devastating and disabling medical conditions affecting wounded members of the military. Veterans Affairs Healthcare System (VA) is the single largest SCI healthcare provider in the nation. In spite of the presence of a caregiver, accessing SCI specialty care may be further challenged with development of complexities evident in chronic SCI, the effects of aging, transportation costs, or the distance to the VA hospital or outpatient services, therefore, methods to facilitate improved access are very crucial. VA virtual health services use technology and health informatics to provide Veterans with better access and more effective care management. The VANJHCS SCI healthcare team (HCT) has successfully implemented Veteran-centered care for the SCI/D population that views Veterans and their caregivers as one system that works in partnership with the HCT. Through this partnership described as "The Triangle of Healthy Caregiving", the HCT incorporates the use of virtual care technologies in their delivery of primary care and specialty services directly to the Veteran and/or caregiver based on clinical needs which have been identified. The proposed project will qualitatively assess SCI Veterans', their caregivers' and VA healthcare team's perspectives and experiences in the "Triangle of Healthy Caregiving for SCI Veterans" to determine the benefits, challenges and outcomes for everyone involved in the intervention.

15. SUBJECT TERMS

Spinal Cord Injury, Veterans, Clinical Video Technology, Quality of Life, SCI, Department of Veterans Affairs, VA, Caregiving

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Unclassified	Unclassified	Unclassified			

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

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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 a debilitating injury that results in chronic paralysis, impaired functioning and drastically altered quality of life (OOL). SCI Veterans' propensity to multiple secondary complications makes a healthy partnership crucial for the success of keeping better health and functional outcomes as well as quality of life. In spite of the presence of a caregiver, accessing SCI specialty care may be further challenged with development of complexities evident in chronic SCI, the effects of aging, transportation costs, or the distance to the VA hospital or outpatient services, therefore, methods to facilitate improved access are crucial. The "Triangle of Healthy Caregiving for SCI Veterans" is a patient-centered intervention which incorporates SCI Veterans' caregivers into the VA SCI healthcare team (HCT) and extends into the homes of SCI Veterans using real-time clinical video teleconferencing (CVT). CVT facilitate video-clinic visits, which include clinical evaluations, therapy (physical/occupational), or supportive services (e.g., social work). The goal of the current study is to qualitatively assess the acceptability and utilization of the "Triangle of Healthy Caregiving for SCI Veterans" intervention with SCI Veterans, caregivers, and healthcare teams to modify, improve, and refine the "Triangle of Healthy Caregiving for SCI Veterans" intervention. The direct or indirect impact of the "Triangle of Healthy Caregiving for SCI Veterans" intervention has not yet been determined.

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

Spinal Cord Injury, Veterans, Clinical Video Technology, Quality of Life, SCI, Department of Veterans Affairs, VA, Caregiving

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.

Study Aim(s):

The research team hopes to assess the acceptability and utilization of the "Triangle of Healthy Caregiving for SCI Veterans" by evaluating these three specific aims and will integrate the findings to prepare a summary of the findings for dissemination:

- 1. Evaluate SCI Veterans experiences in the "Triangle of Healthy Caregiving for SCI Veterans".
- 2. Evaluate the SCI Veterans caregivers' experience receiving support in the "Triangle of Healthy Caregiving for SCI Veterans".

3. Evaluate the VA healthcare team's experience delivering healthcare and providing supportive services using the "Triangle of Healthy Caregiving for SCI Veterans".

STATEMENT OF WORK PROPOSED START DATE Aug 30, 2017

Site 1:	VA New Jersey Health Care System (VANJHCS)
	East Orange Campus
	385 Tremont Avenue,
	East Orange, NJ 07018
	PI: Carol Gibson-Gill, MD

Phase I (SCI Veterans/Telehealth Coordinators Observations and	Timeline	Completion
Installations) Major Task 1: Preparing to launch study	Months	Dates
Initiate weekly research team meetings to plan study kick-off,	1-3	8/27/17
management and logistics	1-3	0/2//1/
Research team and consumer volunteers study kick-off and planning	1-3	9/8/17
meeting	1-3	2/0/17
Submit for WOC	1-3	10/1/17
Finalize consent form & human subjects protocol	1-3	10/17/17
Submit to VANJHCS IRB application	1-4	11/17/17
Submit for Military 2 nd level IRB review (ORP/HRPO)	5-9	2/27/18
Initiate staff training	3-12	10/1/17
Milestone Achieved: Local IRB Exemption/R&D Approval	4-5	1/3/18-
r		2/28/18
Milestone Achieved: HRPO/ACURO Approval	9-10	2/27/18
Phase I (SCI Veterans/Telehealth Coordinators Observations and		
Installations)		
Major Task 2: Qualitative review of enrollment and installation into		
the "Triangle of Healthy Caregiving for SCI Veterans"		
Research team weekly meetings to address study management,	Weekly	"Ongoing"
procedures, and logistics	10.11	0/20/17
Meet with consumer volunteers to review CVT enrollment and	10-11	9/28/17
installation interviews and observation instruments	11 10	4/10/10
Conduct 2 in-depth interviews with VANJHCS Telehealth Coordinators	11-12	4/12/18
Finalize SCI Veterans semi-structured interview questions	17	8/1/18
Conduct 10 observations of SCI Veteran patient enrollment in the	11-16	"Ongoing"
"Triangle of Healthy Caregiving for SCI Veterans"	11 10	911891118
Conduct 10 observations of SCI Veteran home installation of the CVT	11-16	"Ongoing"
equipment/devices		8.8
Milestone achieved: Qualitative review of enrollment and installation	11-16	"Ongoing"
into the "Triangle of Healthy Caregiving for SCI Veterans" completed		
Conduct qualitative data analyses	11-16	"Ongoing"
Phase III (SCI Clinicians Focus Group)		
Major Task 5: Conduct 1 focus group with VANJHCS virtual	27-29	
healthcare team professionals		

Research team weekly meetings to address study management,	Weekly	"Ongoing"
procedures, and logistics		
Meet with consumer volunteers to review focus group script	27	2/8/18
Finalize focus group script	27-29	6/1/18
Screen and consent VANJHCS virtual healthcare team professionals	27-29	6/6/18
Conduct focus group with VANJHCS virtual healthcare team	27-29	6/6/18
professionals		
Milestone Achieved: focus group with VANJHCS virtual healthcare	27-29	6/6/18
team professionals		
Conduct qualitative data analyses	27-29	"Ongoing"

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.

Goals/Milestones

Phase I (SCI Veterans/Telehealth Coordinators Observations and Installations)

Major Task 1: 2017 Goal – Prepare to launch the study

- ✓ The Research team recruited and hired the members of the research team (Research Coordinator, Research Assistant) and initiated the VA Without Compensation (WOC) clearance process. Despite an unexpected delay this WOC status was obtained.
- ✓ The VA New Jersey Healthcare System (VANJHCS) research team held weekly research team meetings to address study management, procedures, and logistics across sites.
- ✓ Yasheca Ebanks-Williams was recruited to be the Research Coordinator and obtained log-in credentials for the VA's secure network and medical records system, outlook e-mail addresses and was briefed on the study requirements so that she could formalize the study consent form and human subject's protocol for the initial submission for the local VA IRB approval.
- ✓ Study staff and all listed collaborators began all required VA Research training for study initiation
- ✓ The research team identified key possible members that could be recruited for the Community Advisory Board (CAB). They were each contacted and invited to be on the CAB. An introductory orientation was provided to each potential CAB member via phone to the study by Joyce Williams. A survey was then conducted to get dates for the first CAB meeting to be held. After all parties agreed on a date, a presentation was made to the CAB by Dr. Carol Gibson-Gill and Joyce Williams about the study's goals and aims. All CAB members provided input as to how we should better target the Spinal Cord Injury population for subject recruitment.
- ✓ After receiving notification from the local IRB Office, the study was advised that we would be IRB Exempted according to category 2 exemption policies and were directed to conduct an initial submission to the local Office of Research & Development for approval and it was granted. Thereafter submission for Military 2nd level IRB review (ORP/HRPO) approval and thus was granted as well.

Major Task 2: 2018 Goal- Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans

Initiated Phase I data collection which involves Telehealth Coordinator Interviews. These interviews were conducted to gain an understanding of the perceptions about the "Triangle of Healthy Caregiving for SCI Veterans" program using Clinical Video Technology in the provision and the ways that impacts the delivery of healthcare. By doing this, the research team was able to identify that

there was no actual manual of procedures for the enrollment process of veterans on the Triangle of Healthy Caregiving for SCI program which led the research team to begin working with the Telehealth Coordinators to develop a standardized manual of procedures (MOP). This is in progress and the completion of the data collection for initial part of Phase I, which involved Telehealth Coordinator Interviews, was completed.

- ✓ Major Task 5: 2018 Phase III Goal- Qualitative Data Analyses is ongoing.
- ✓ There was a technology upgrade by VHA and as a result delays occurred. The study team decided
 to completed Phase III data collection with the local SCI Virtual Healthcare Team and ensure data
 quality checks were in place. Phase III, which was inclusive of VANJHCS Virtual HealthCare Team
 Professionals Focus group, was conducted on June 2018 with ten willing participants.

Goals not met:

✓ The completion of the latter part of Phase I, which involves Observations of Enrollment & Installations, has not been achieved due to the technology upgrade that forced us to delay the initiation

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.

The following trainings were provided and completed in Year 1-Institutional Review Board (IRB) Training, Clinical Video Technology Study Staff Training, RedCAP Data Repository System Study Staff Training, Spinal Cord Injury- Functional Index (SCI-FI) Study Staff Training, Human Subjects Research at the VA Seminar, VA Research Role of Privacy & Information Security in Research Workshop, VA HIPAA Training. Research Assistant Data Collection and Quality Control Training.

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.

"Not	hing	to k	Report"
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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 Research Team has decided to continue the ongoing processes of the Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans program" as promised to conclude the items of Phase I. We will also initiate the semi-structured interviews for the SCI Veterans and their Caregivers as directed in Phase II. Please see the chart below with further details.

STATEMENT OF WORK PROPOSED START DATE Aug 30, 2017

Site 1:	VA New Jersey Health Care System (VANJHCS)
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	East Orange, NJ 07018
	PI: Carol Gibson-Gill, MD

Phase I (SCI Veterans/Telehealth Coordinators Observations and Installations)	Timeline
Major Task 2: Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans"	Months
Conduct 10 observations of SCI Veteran patient enrollment in the "Triangle of Healthy Caregiving for SCI Veterans"	11-16
Conduct 10 observations of SCI Veteran home installation of the CVT equipment/devices	11-16
Milestone achieved: Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans" completed	11-16
Conduct qualitative data analyses	11-16
Phase II (Semi-structured Interviews for Veterans)	
Major Task 3: Semi-structured interviews with 35-40 SCI Veterans enrolled in the "Triangle of Healthy Caregiving for SCI Veterans" program	18-22
Research team weekly meetings to address study management, procedures, and logistics	Weekly
Meet with consumer volunteers to review SCI Veterans semi- structured interviews	16-17
Finalize SCI Veterans semi-structured interview questions	17
Recruit and consent 35-40 SCI Veterans to participant in semi- structured interviews	17-22
Complete 35-40 SCI Veterans to participant in semi-structured interviews	18-22
Milestone(s) to Achieve: Semi-structured interviews with 35-40 SCI	18-22
Veterans enrolled in the "Triangle of Healthy Caregiving for SCI Veterans" program completed	
Conduct qualitative data analyses	17-26

Phase II (Semi-structured Interviews for Veteran Caregivers)	
Major Task 4: Semi-structured interviews with 25-30 caregivers of SCI Veterans enrolled in the "Triangle of Healthy Caregiving for SCI Veterans" program	19-24
Research team weekly meetings to address study management, procedures, and logistics	Weekly
Meet with consumer volunteers to review caregiver semi- structured interview questions	19-20
Finalize caregivers semi-structured interview questions	19-24
Recruit and consent 25-30 caregivers to participant in semi- structured interviews	19-24
Complete 25-30 caregivers to participant in semi-structured interviews	19-24
Milestone Achieved: Semi-structured interviews with 35-40 SCI Veterans enrolled in the "Triangle of Healthy Caregiving for SCI Veterans" program completed	19-24
Conduct qualitative data analyses	19-28

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).

Based on interviews with the Telehealth Coordinators and the rest of the SCI Virtual HealthCare Team, the research study staff identified a gap in the current program. There is no standardized process to enroll veterans on the Triangle of Healthy Caregiving for SCI program. There is a need to develop a manual of procedures to better assists our veterans and their caregivers when enrolling in to the Triangle of Healthy Caregiving for SCI program. This manual of procedures is now being developed by the current Virtual Healthcare Team and the study staff of this project.

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.

"Nothing to Report"

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.

"Nothing to Report"

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.

• Timeline changes occurred due to administrative issues-

Some local delay in WOC clearance process while hiring the Research Assistant.

• Timeline changes due to administrative issues-

Some local administrative changes with Big Enterprises due to transcription services Data Use Agreement delay.

• Timeline changes due to Data Use Agreement issues-

Some local administrative changes with VA Salt Lake City (VASLC Centralized Transcription Services due to Data Use Agreement requiring a Memorandum of understand to receive payment from a non-federal entity).

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.

Year 1:

Delay 1: WOC clearance process while hiring the Research Assistant

<u>Corrective Action:</u> There was nothing the Research Team could have done to expedite this process. So, the Research Assistant had to switch her start date to 30 days later than anticipated.

Delay 2: BIG Enterprises transcription services affiliate contract was terminated with VANJHCS. **Corrective Action:** Since this was unexpected the study team sought out possible transcription services that could be contenders to transcribe with the VA for this study.

Delay 3: An agreement was formed to establish the transcription terms and conditions under which the VA New Jersey Health Care System (VANJHCS) - Spinal Cord Injury and Disorder Service, Carol Gibson-Gill and VA Salt Lake City (VASLC) Centralized Transcription Services Program. the VASLC does not require a memorandum of understanding (MOU) to receive payment for transcribing the recorded interviews but we were informed that our local research institute which holds all non-VA funded research projects, "The Veterans Biomedical Research Institute", does have this requirement and its Executive Director had to work with VANJHCS Legal Team to finalize a MOU with VASLC.

<u>Corrective Action:</u> Since March 2018 a study MOU has been created and was in attorney review awaiting approval. Despite this unanticipated delay we have completed both telehealth coordinator interviews and await this formal approval to finalize this data collection method. In the meantime, the research team decided to have the Research Assistant do the transcribing of the Telehealth Coordinator interviews.

Delay 4: Transcription Services:

The agreement that was formed to establish the transcription terms and conditions under which the VA New Jersey Health Care System (VANJHCS) - Spinal Cord Injury and Disorder Service, Carol Gibson-Gill and VA Salt Lake City (VASLC) Centralized Transcription Services Program (CTSP) was withdrawn (due to administrative issues with CTSP).

Corrective Action:

To prevent further delays the research team has identified another transcription company that had been utilize by our collaborators and a completed Non-Federal DUA has been sent to VANJHCS Information System Security Office (ISSO) AND Privacy Office (PO) to form an agreement with a VA approved "file sharing site" SFTP: SAFE, now that "Keystrokes BSC," a different transcription service, has been secured for data collection.

Delay 5: Study Equipment Logistic delay at VANJHCS:

Due to the change of positions in the logistics department the study laptop has been waiting to be tagged by VANJHCS Logistics staff.

Corrective Action:

According to the IT rep, a request has been sent to confirm the status of the tag of the study laptop.

Delay 6: Phase I: Observations of Enrollment/Equipment Installations delay at VANJHCS:

A major change in Clinical Video Technology (CVT) modalities to be used was made by the VHA. This required that the SCI Virtual Healthcare Team were trained on the latest CVT modality that is being offered by VHA Telehealth: VA Video Conferencing (VVC). The Virtual Healthcare team has been asked to upgrade

all current SCI Veterans to the newly activated modality, if the veterans are willing. Dr. Gibson-Gill and her study team have decided to validate the steps that are required to enroll the SCI Veterans on the VVC by conducting a trial with 2-3 willing Community Advisory Board members as they went through the upgrade themselves.

Corrective Action:

We are conducting mock enrollment and installation sessions with 2-3 members of the community advisory board to validate the accuracy of the Triangle of Healthy Caregiving SCI service enrollment and installation checklists before the research team officially begins observations with SCI Veterans.

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.

Significant changes in use or care of human subjects

"Nothing to Report"	
Significant changes in use or care of vertebrate animals	
"Nothing to Report"	

Significant changes in use of biohazards and/or select agents

"Nothing to Report"

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).

"Nothing to Report"

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).

"Nothing to Report"

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.

-Triangle of Healthy Caregiving for Spinal Cord Injured Veterans- Abstract <u>accepted</u> to be presented at the International Planetree Conference. 10/2018

• 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.

"Nothing to Report"

• Technologies or techniques

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

"Nothing to Report"

• 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.

"Nothing to Report"

• 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.

"Nothing to Report"

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: Carol Gibson-Gill, MD
Project Role: Principal Investigator

Nearest person month worked: 12 Months

Contribution to Project: Dr. Gibson-Gill has performed in the role of overseer in all aspects of the research project. Her responsibility is to oversee all aspects of the project taking place at the Veterans Administration New Jersey Healthcare System (VANJHCS). She has participated in regular study conference calls to monitor the overall study progress (e.g., development of the focus group/in-depth interview script), provided methodological and content about VA SCI veterans throughout each stage of the study.

Funding Support: Spinal Cord Injury - Qualitative Research Award, Log

#SC160198

Name: Denise Fyffe-Thomas PhD

Project Role: Nearest person month worked:Co-Investigator
12 Months

Contribution to Project: Dr. Fyffe is a Senior Research Scientist at the Kessler Foundation and has and will continue to serve as the Co-Investigator for the study. Dr. Fyffe has devoted 20% of her effort throughout the award period to the proposed research activities. Dr. Fyffe has participated in regular study meetings to monitor the overall study progress along with Dr. Carol Gibson-Gill with the study site. She has conducted the in-depth interviews with the CVT administrative technicians (Telehealth Coordinators); supervise the enrollment procedures and home-observations of the CVT device and equipment installations at SCI Veterans homes. Dr. Fyffe assisted as an oversight in the training of the Research Assistant in qualitative data collection, management and quality control. Dr. Fyffe moderated the Clinician focus group. She also is the head of coordinating and perform the qualitative analyses.

Funding Support: Spinal Cord Injury - Qualitative Research Award, Log

#SC160198

Name: Joyce Williams, LCSW

Project Role:Co-Investigator **Nearest person month worked:**12 Months

Contribution to Project: Ms. Williams is the Spinal Cord Injury and Disorders

Coordinator for the VA NJ Healthcare Systems. She provides therapeutic services for spinal cord veterans through psychosocial assessment and on-going case management for our veterans and caregivers support groups. She utilizes the virtual care technologies actively in the care she delivers to the veterans and their caregivers. She has been actively involved in tracking participant enrollment, working with the Research Assistant to maximize participation while ensuring data

integrity for information gathered from medical records, interviews, and focus groups. She will work along with the Research Coordinator to coordinate recruitment at the VA NJ SCI Center **Funding Support:**Spinal Cord Injury - Qualitative Research Award, Log

#SC160198

Name: Yasheca Ebanks-Williams, MS, CCRC

Project Role: Research Coordinator

Nearest person month worked: 12 Months

Contribution to Project: Mrs. Ebanks-Williams manage study data collection, including tracking participant enrollment, working with the Research Assistant to maximize participation while ensuring data integrity for information gathered from medical records, interviews, and focus groups. Mrs. Ebanks-Williams coordinated the recruitment at the study site, engaged in qualitative data collection, maintaining data quality analyze qualitative data for emerging themes, draft codebooks, also in the development of dissemination material and professional publications. Mrs. Ebanks-Williams also has assisted in training the Research Assistant in data collection methods.

Funding Support: Spinal Cord Injury - Qualitative Research Award, Log

#SC160198

Name: Nicole Jones, BS
Project Role: Research Assistant

Nearest person month worked: 12 Months

Contribution to Project: Ms. Jones was responsible for the recruitment of the CAB members and Phase I data collection. Ms. Jones also assisted with preparation of dissemination of study findings per phase, as well as the transcribing of study audio files.

Funding Support: Spinal Cord Injury - Qualitative Research Award, Log

#SC160198

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.

"Nothing to Report"

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)

<u>Partner's contribution to the project</u> (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.

Kessler Foundation Inc. 120 Eagle Rock Avenue, Suite 100 East Hanover, NJ 07936

Collaborator Denise Fyffe-Thomas is the Co-Investigator for this study.

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.

Please see the attached documents (i.e.... Study questionnaires and surveys administered and International Planetree Conference accepted abstract for your review.)

Triangle of Healthy Caregiving for Spinal Cord-Injured Veterans

Log #: SC160198 Award #W81XWH-16-SCRIP-QRA

PI: Carol Gibson-Gill, M.D. Org: Veterans Affairs New Jersey Health Care System (VA NJHCS) Award Amount: \$527,245.00

Study Aim(s)

The research team hopes to assess the acceptability and utilization of the "Triangle of Healthy Caregiving for SCI Veterans" by evaluating these three specific aims and will integrate the findings to prepare a summary of the findings for dissemination:

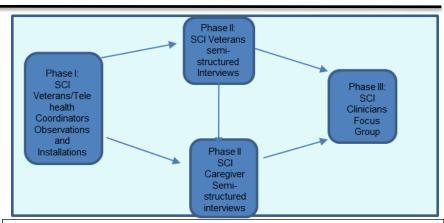
- Evaluate SCI Veterans experiences in the "Triangle of Healthy Caregiving for SCI Veterans".
- 2. Evaluate the SCI Veterans caregivers' experience receiving support in the "Triangle of Healthy Caregiving for SCI Veterans".
- 3. Evaluate the VA healthcare team's experience delivering healthcare and providing supportive services using the "Triangle of Healthy Caregiving for SCI Veterans".

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.

Timeline and Cost					
Activities	CY	17	18	19	20
Observations and Installations					
Complete Phase II Veterans & Family Caregivers semistructured interviews					
Complete SCI clinicians focus groups					
Evaluation focus	groups				
Estimated Budge (\$524,245.00)	et	\$137,006	\$253,233	91,338	45,668

Annual Report Period Year One: 7/15/2017-8/14/2018



Accomplishments: Appropriate staff hired and trained; Community Advisory Board convened. Local R&D and HRPO Approval. Phase I -Telehealth Coordinators recruited. Phase I Telehealth Coordinators Interviews completed. Preparation for the initiation of 10 observations of SCI Veteran enrollment during Phase I. Phase III Virtual Healthcare Team Focus Group completed.

Goals/Milestones

CY17 Goal - Prepare to launch the study

- ✓ Initiated research team meetings to plan study procedure and develop the content of the data collection instruments
- ✓ Standardized study operating procedures for each phase of the study

CY18 Goals – Initiated Phase I data collection (which involves Telehealth Coordinator Interviews & Observations of Enrollment and Installations)

- ✓ Completed Phase III data collection and ensured data quality checks are in place
- ✓ Completed data collection for initial part of Phase I (which involved Telehealth Coordinator Interviews).
- ✓ Initiated data collection process to complete the latter part of Phase I (which involves Observations of Enrollment & Installations)
- ✓ Qualitative Data Analyses- Ongoing

CY19 Goals-

- Phase II data collection and ensure data quality checks are in place
- Complete data collection, data cleaning, analysis and dissemination

Comments/Challenges/Issues/Concerns

• Timeline changes due to administrative issues (e.g. local administrative changes with due to transcription services delay).

Budget Expenditure to Date

Actual Expenditure \$98,726.56

ID NUME	BER:		Date:			
SCI Clinician Demographic Form						
clinician, Please a	ons: stionnaire is going to ask some background such as your age, sex, professional discipli nswer these questions honestly. You may re	ne, and length of time in yo	our current position.			
[CLD_1] a	_	777 = Don't know	999 = Refused			
[CLD_2] :	sex					
Would yo	u identify yourself as?					
1	Male					
0	Female					
77	Z Don't know					
99	Refused					
[CLD_3]	brthpl					
In what co	ountry were you born?					
1	United States					
2	Other Country → Complete [CLD_3a]					
77	7 Don't know					
99	Refused					
[C	LD_3a] brthpl_yrus					
W	hat year did you move to the United States?	7777 = Don't know	9999 = Refused			
[CLD_4] I	lang					
What lang	guage do you mainly speak at home?					
1	English					
2	Spanish					
3	Other language → Complete [CLD_4a]					
77	Don't know					
99	Refused					
[C	CLD_4a] lang_oth					
Pl	ease specify which other language:					

SCI Clinician Focus Group: Triangle of Healthy Caregiving for Spinal Cord Injured Veterans Version Date: 16 April 2018

ID NUMBER:	Date:
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SCI Clinician Demographic Form

[CLD_5] hisp

Are you of Hispanic, Latino, or Spanish origin or descent?

- Yes
- 0 No
- 77 Don't know
- 99 Refused

[CLD 6] race

We would like to know how you describe yourself racially. Do you consider yourself to be...? Mark all that apply.

- 1 American Indian or Alaska Native
- 2 Asian
- 3 Black or African American
- 4 Native Hawaiian or Other Pacific Islander
- 5 White or Caucasian
- 6 Other → Complete [CLD_6a]
- 77 Don't know
- 99 Refused

[CLD_6a] race_oth

Please specify other race:

[CLD_7] marstat

What is your marital status?

- 0 Single
- 1 Married
- 2 Divorced
- 3 Widowed
- Living with partner 4
- 77 Don't know
- Refused 99

[CLD_8] degree

What is the highest academic degree you've earned?

- 1 Technical (vocational) certificate
- 2 Associate's degree
- 3 **Bachelor Degree**
- 4 Master's Degree
- 5 Specialist
- 6 M.D., Ph.D., Ed.D., or other professional degree (J.D., D.D.S)
- 7 Other → Complete [CLD_8a]

Version Date: 16 April 2018

	<u>SCI</u>	Clinician Demogra	phic Form	
[CL	D_8a] degree_oth	-		
	ase specify other degree:			
D_9] cl				
•	r CURRENT job title?			
1	Physician (Physiatrist)			
2	Nurse			
3	Physical Therapist			
4	Recreational Therapist			
5	Occupational Therapist			
6	Psychologist			
7	Social Worker			
8	Respiratory Therapist			
9	Other → Complete [CLI)_9aj		
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SCI Clinician Focus Group: Triangle of Healthy Caregiving for Spinal Cord Injured Veterans Version Date: 16 April 2018

ID NUMBER:	Date	e:				
SCI Clinician CVT Assessment						
Instructions:						
This questionnaire is going to ask some questions about your excaregivers.	perience	e using CVT with SCI Veterans and				
Please answer these questions honestly. You may refuse to answ	ver any o	question you aren't comfortable				
Please select the response that best describes your experience using veterans living with a spinal cord injury.	CVT in t	he provision of rehabilitative care to				
answering.						
[CVTQ_1a] freq						
How often do you use CVT with SCI veterans?	□ 4	Monthly				
(Pick one)	Пз	Weekly				
	☐ 2	Daily				
	□ 1	As needed (explain)				
	□ 77	Don't know				
	□ 99	Refused				
[CVTQ_1b] freq						
How often do you use CVT with SCI Caregivers (family and/or skilled workers)?	□ 4	Monthly				
,	□ 3	Weekly				
	□ 2	Daily				
		As needed (explain)				
	□ 77	Don't know				
	□ 99	Refused				
[CVTQ_2] mod						
Which telehealth modality are you most familiar with?	□ 5	Myhealthevet/secure messaging				
(Pick one)	□ 4	BL Tablets				
	Пз	VA Video Connect (VVC)				
	□ 2	Home telehealth: red alerts				
	□ 1	Jabber				
	□ 77	Don't know				
	□ 99	Refused				
[CVTQ_3] diff	,					
How easy or difficult do you find it to use CVT with SCI veterans and	Пз	Easy				

ID NUMBER:	Date	e:		
SCI Clinician CVT Assessment				
caregivers?	□ 2	Somewhat difficult		
(Pick one)	□ 1	Difficult		
	□ 77	Don't know		
	99	Refused		

ID NUMBER:	Date:	
	26.0.	

		<u> </u>		:	
Always	Often	Sometimes	Rarely	Never	Item Score
□ 4	□ 3	□ 2	□ 1	□ 0	
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ID NUMBER:		Date:						
SCI Clinician CVT Assessment								
15. How often do you have connectivity issues w using VVC?	hen 🗆 4	□ 3	□ 2	□ 1	□ 0			
16. How often do you have connectivity issues w using the BL tablets?	hen 🗆 4	□ 3	□ 2	□ 1	□ 0			
17. If you are having any connectivity issues how do you resolve it yourself?	r often □ 4	□ 3	□ 2	□ 1	□ 0			
18. If you are having any connectivity issues, how do you get help from the SCI RN Telehealth Coordinator or /and the SCI LPN Telehealth technician?	Care 🖂	□ 3	□ 2	□ 1	□ 0			
						Item Total		

_Score

"The Triangle of Healthy Caregiving for SCI Veterans"

2018 Planetree International Conference on Person-Centered Care

<u>Authors:</u> Carol Gibson-Gill, MD; Joyce Williams, LCSW; Denise Fyffe, PhD; Yasheca Ebanks, CCRC; Nicole Jones, BS Mathematics; Spinal Cord Injury Department, VA New Jersey HealthCare System

Spinal cord injury (SCI) can be a devastating and disabling medical condition with significant impact on quality of life. Further, an SCI can be very costly on to the patient, their families and healthcare system. The "Triangle of Healthy Caregiving for Spinal Cord Injured Veterans" is a patient-centered intervention which includes the spinal cord injured (SCI) Veterans' caregivers into the VA SCI healthcare team and extends into the home using clinical video teleconferencing (CVT) at the VA New Jersey Health Care System. After our presentation, participants will be able to understand the potential benefits of utilizing a similar intervention at their own institutions. Our presentation will share the voices of the clinicians, caregivers and veterans involved with the intervention. By the end of our presentation, participants will be capable of implementing key elements of clinical video teleconferencing interventions to a seamless care experience for patients and caregivers at their institutions.

Learning Objectives

- 1. Understanding the importance of increasing access to rehabilitative and whole health care for the SCI/D veterans and their caregivers
- 2. Understanding the voices of the veterans, caregivers and clinicians currently involved in the "Triangle of Healthy Caregiving for SCI Veterans" intervention.
- 3.Understanding the benefits of CVT as a patient-centered intervention to improve access to clinical rehabilitation in the homes of SCI patients and their caregivers.