

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 Affairs New Jersey Healthcare System  
385 Tremont Ave East Orange, NJ 07018

REPORT DATE: August 2020

TYPE OF REPORT: Annual Report

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

DISTRIBUTION STATEMENT: Approved for Public Release;  
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

# REPORT DOCUMENTATION PAGE

Form Approved  
OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. **PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.**

<b>1. REPORT DATE</b> August 2020	<b>2. REPORT TYPE</b> Annual	<b>3. DATES COVERED</b> 7/15/2019 - 7/14/2020
<b>4. TITLE AND SUBTITLE</b>  Triangle of Healthy Caregiving for Spinal Cord- Injured Veterans		<b>5a. CONTRACT NUMBER</b> W81XWH-17-1-0262
		<b>5b. GRANT NUMBER</b> SC160198
		<b>5c. PROGRAM ELEMENT NUMBER</b>
<b>6. AUTHOR(S)</b> Carol Gibson-Gill, MD, Joyce Williams, LCSW, Denise Fyffe, PHD  E-Mail: <a href="mailto:Carol.Gibson-Gill@Va.Gov">Carol.Gibson-Gill@Va.Gov</a> ; <a href="mailto:Joyce.Williams9@va.gov">Joyce.Williams9@va.gov</a> ; <a href="mailto:Denise.Fyffe@Va.gov">Denise.Fyffe@Va.gov</a>		<b>5d. PROJECT NUMBER</b>
		<b>5e. TASK NUMBER</b>
		<b>5f. WORK UNIT NUMBER</b>
<b>7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)</b>  Veterans Affairs New Jersey Healthcare System 385 Tremont Ave East Orange, NJ 07018		<b>8. PERFORMING ORGANIZATION REPORT</b>
<b>9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)</b>  U.S. Army Medical Research and Development Command Fort Detrick, Maryland 21702-5012		<b>10. SPONSOR/MONITOR'S ACRONYM(S)</b>
		<b>11. SPONSOR/MONITOR'S REPORT NUMBER(S)</b>
<b>12. DISTRIBUTION / AVAILABILITY STATEMENT</b>  Approved for Public Release; Distribution Unlimited		
<b>13. SUPPLEMENTARY NOTES</b>		

**14. ABSTRACT**

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 using real-time virtual care technologies (VCT). The goal of our study is to qualitatively assess the acceptability and utilization of this patient-centered intervention thereby identifying the impact of the intervention and make recommendations to improve, modify, and refine this intervention.

Our preliminary findings suggest all study participants like the use of VCT in healthcare delivery. The reported benefits was the convenience and having access to the HCT without the burden of traveling and easy Caregiver involvement. Successful VCT visits requires quickly troubleshooting technical issues, ongoing education and support by the Telehealth Coordinators, users being comfortable and having access to technology. Caregivers’ physical assistance in using technology for the Veterans with higher spinal cord injury levels (high tetraplegia) was also emphasized, thereby contributing to lack of privacy and control during visits for those who are dependent on Caregivers.

Findings highlight the value of the “users” voice when developing processes, policies and equipment. There should also be a priority focus on consistent education to the veterans about the benefits of using VCT.

**15. SUBJECT TERMS**

Spinal Cord Injury, Veterans, Caregivers, Clinical Video Technology, Virtual Care technologies, Quality of Life, Benefits, Healthcare delivery, Challenges, Health outcomes

<b>16. SECURITY CLASSIFICATION OF:</b>			<b>17. LIMITATION OF ABSTRACT</b>	<b>18. NUMBER OF PAGES</b>	<b>19a. NAME OF RESPONSIBLE PERSON</b>
U					<b>13</b>
<b>a. REPORT</b>	<b>b. ABSTRACT</b>	<b>c. THIS PAGE</b>	UU		<b>19b. TELEPHONE NUMBER</b>
U	U	U			(include area code)

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

## TABLE OF CONTENTS

	<u>Page</u>
1. Introduction	5
2. Keywords	5
3. Accomplishments	5
4. Impact	8
5. Changes/Problems	9
6. Products	10
7. Participants & Other Collaborating Organizations	11
8. Special Reporting Requirements	13
9. Appendices	13

## 1. INTRODUCTION:

Spinal cord injury (SCI) is a debilitating injury that results in chronic paralysis, impaired functioning and drastically altered quality of life (QOL). 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 conferencing (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 the healthcare teams to modify, improve, and refine this intervention as the direct or indirect impact of the "Triangle of Healthy Caregiving for SCI Veterans" intervention has not yet been determined.

## 2. KEYWORDS:

Spinal Cord Injury, Veterans, Caregivers, Clinical Video Technology, Virtual Care technologies, Quality of Life, Benefits, Healthcare delivery, Challenges, Health outcomes

## 3. ACCOMPLISHMENTS:

### What were the major goals of the project?

#### Study Aims:

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 SCI Healthcare Team's experience delivering healthcare and providing supportive services using the "Triangle of 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 Gill, MD

<b>Phase I (SCI Veterans/Telehealth Coordinators Observations and Installations)</b>	<b>Timeline</b>	<b>% Completion</b>
<b><i>Major Task 1: Preparing to launch study</i></b>	Months	
Initiate weekly research team meetings to plan study kick-off, management and logistics	1-3	100%
Research team and consumer volunteers study kick-off and planning meeting	1-3	100%
Submit for WOC	1-3	100%
Finalize consent form & human subjects' protocol	1-3	100%
Submit to VANJHCS IRB application	1-4	100%
Submit for Military 2 <sup>nd</sup> level IRB review (ORP/HRPO)	5-9	100%
Initiate staff training	3-12	100%
Milestone Achieved: Local IRB Exemption/R&D Approval	4-5	ANNUAL
Milestone Achieved: HRPO/ACURO Approval	9-10	100%
<b>Phase I (SCI Veterans/Telehealth Coordinators and Observations of Enrollment)</b>		
<b><i>Major Task 2: Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans"</i></b>		
Research team weekly meetings to address study management, procedures, and logistics	Weekly	"Ongoing"
Meet with consumer volunteers to review CVT enrollment and installation interviews and observation instruments	10-11	100%
Conduct 2 in-depth interviews with VANJHCS Telehealth Coordinators	11-12	100%
Finalize SCI Veterans semi-structured interview questions	17	100%
Conduct 10 observations of <i>SCI Veteran patient enrollment</i> in the "Triangle of Healthy Caregiving for SCI Veterans"	11-16	100%
Conduct 10 observations of SCI Veteran home installation of the CVT equipment/devices	11-16	100%
Milestone achieved: Qualitative review of enrollment and installation into the "Triangle of Healthy Caregiving for SCI Veterans" completed	11-16	100%
Conduct qualitative data analyses	11-16	"Ongoing"
<b>Phase III (SCI Clinicians Focus Group)</b>		
<b><i>Major Task 5: Conduct 1 focus group with VANJHCS virtual healthcare team professionals</i></b>		
Research team weekly meetings to address study management, procedures, and logistics	Weekly	"Ongoing"
Meet with consumer volunteers to review focus group script	27	100%
Finalize focus group script	27-29	100%
Screen and consent VANJHCS virtual healthcare team	27-29	100%

professionals		
Conduct focus group with VANJHCS virtual healthcare team professionals	27-29	100%
Milestone Achieved: <i>focus group with VANJHCS virtual healthcare team professionals</i>	27-29	100%
Conduct qualitative data analyses	27-29	Ongoing
<b>Phase II (Semi-structured Interviews for Veterans)</b>		
<b>Major Task 3: Semi-structured interviews with 35-40 SCI Veterans enrolled in the “Triangle of Healthy Caregiving for SCI Veterans” program</b>		
Research team weekly meetings to address study management, procedures, and logistics	Weekly	Ongoing
Meet with consumer volunteers to review SCI Veterans semi-structured interviews	16-17	100%
Finalize SCI Veterans semi-structured interview questions	17	100%
Recruit and consent 35-40 SCI Veterans to participant in semi-structured interviews	17-22	100%
Complete 35-40 SCI Veterans to participant in semi-structured interviews	18-22	100%
Milestone(s) to Achieve: <i>Semi-structured interviews with 35-40 SCI Veterans enrolled in the “Triangle of Healthy Caregiving for SCI Veterans” program completed</i>	18-22	100%
Conduct qualitative data analyses	17-26	Ongoing
<b>Major Task 4: Semi-structured interviews with 25-30 Caregivers of SCI Veterans enrolled in the “Triangle of Healthy Caregiving for SCI Veterans” program</b>		
Research team weekly meetings to address study management, procedures, and logistics	Weekly	Ongoing
Finalize caregivers semi-structured interview questions	19-24	100%
Recruit and consent 25-30 caregivers to participant in semi-structured interviews	19-24	100%
Complete 25-30 caregivers to participant in semi-structured interviews	19-24	100%
Milestone Achieved: Semi-structured interviews with 35-40 SCI Veterans enrolled in the “Triangle of Healthy Caregiving for SCI Veterans” program completed	19-24	100%
Conduct qualitative data analyses	19-28	ongoing
<b>Major Task 6: Triangulate Qualitative Data, Practice Recommendations and Dissemination</b>		
Review of coding, triangulation of data sources, strategies for identifying other key patterns and findings for dissemination efforts	30-36	ongoing
Develop practices policy recommendations	30-36	pending
Disseminate findings at national professional meetings (e.g., abstracts, presentation, publications)	30-36	ongoing
Milestones Achieved: Analyses completed; Practice Recommendations developed; Findings disseminated at professional meetings and publications	30-36	ongoing

## What was accomplished under these goals?

### Goals/Milestones

Major Task 4: Semi-structured interviews with 25-30 Caregivers of SCI Veterans enrolled in the “Triangle of Healthy Caregiving for SCI Veterans” program.

- We recruited and completed the semi-structured interviews with the Caregivers during this period.

We provided an update on the study to our Veterans-Consumer Advisory Board during this period. We shared some of the data we have collected and the lessons we have learned so far. They found the information very useful and suggested that we conduct more work on this looking at ways to educate more Veterans with SCI on the benefits of using CVT in their healthcare as well as recommending the need to have more Telehealth staff in healthcare systems who would be readily available to assist with technical issues that might arise during the visits via CVT.

#### Major Task 6: Triangulate Qualitative Data, Practice Recommendations and Dissemination

1. Codebook development was completed (see attachment). The codebook includes 6 themes and 44 codes that capture the Veteran and Caregivers experiences and perspectives about CVT.
2. Coders completed their coding training
3. The interview data was imported into NVivo (i.e., the qualitative data analysis software) for analyses
4. Coders were trained in using NVivo
5. Coding reconciliation is on-going for transcripts from interviews that have been coded

A manuscript of the protocol was published in a peer-reviewed journal.

**Goals not met:** We have not completed the qualitative data analyses as we had projected due to several unanticipated issues brought on by changes in the transcription service we had secured initially. There were some issues with the Transcription company agreement with the local VA requiring us to secure a different one. Several transcription companies we researched either could not get the transcripts completed in time for us and/or were extremely costly. This required us having to train the Research Coordinator and Research Assistant to do the transcription for us and then conduct quality assurance on the transcripts before we could start the data cleaning and coding.

Also, during this time, the COVID19 pandemic began which caused some of the research team to experience challenges including family health issues. We also had staff changes during this time requiring us to recruit and interview for a new Research Assistant and Research Coordinator. The onboarding of the new staff has been slow due to the pandemic. We still are trying to get all staff fully onboarded.

#### **What opportunities for training and professional development has the project provided?**

*The following trainings were provided and completed in Year 3- Continuing Education Research Workshops by the VA Research Office, Training on transcribing, data cleaning and coding provided by Dr. Fyffe to the Research team.*

**How were the results disseminated to communities of interest?** Nothing to report

**What do you plan to do during the next reporting period to accomplish the goals?** The research team submitted a formal request for a no cost extension to be able to complete this major task. We hope to be granted that courtesy to be able to complete the task. We have recruited and hired a Research Coordinator who we plan to have onboarded and trained to start working with us to complete the data cleaning and analysis, prepare recommendations for dissemination and the goals of this major task.

#### **4. IMPACT:**

##### **What was the impact on the development of the principal discipline(s) of the project?**

The participants provided useful information that can be used to positively influence the development of processes, policies and equipment that would make implementation of virtual care technologies in the delivery of care for Veterans with SCI easily accomplished with the goal of improving healthcare outcomes (including cost) in this high risk Veteran population. Looking at the data, we have developed a Data codebook which includes themes and codes that capture the Veterans and their Caregivers' experiences and perspectives about using of CVT in their healthcare.

**What was the impact on other disciplines?**

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

Although the data cleaning and analysis are not completed, we expect that when all done, we will be able to make recommendations that would be helpful in the expansion of clinical video technology to other healthcare workers who serve Veterans with spinal cord injury.

**What was the impact on technology transfer?**

*"Nothing to Report"*

**What was the impact on society beyond science and technology?**

*"Nothing to Report"*

**5. CHANGES/PROBLEMS:**

**Changes in approach and reasons for change**

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

*Nothing to report*

**Actual or anticipated problems or delays and actions or plans to resolve them**

Changes in transcription company service occurred and our plan we devised to resolve the transcription issue was to train our research staff to do the transcribing ourselves and do our own quality checks on the transcription before we could do the data analysis.

**Changes that had a significant impact on expenditures**

*Due to staffing issues, we had to ask our research assistant to give us more hours to work on the transcription process.*

**Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents**

**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**

**Journal publications.**

Gibson-Gill C, Williams J, Fyffe DC. Triangle of Healthy Caregiving for Spinal Cord Injured Veterans. JMIR Research Protocols. 2020 May; 9(5): e14051, 1-11 (PUBLISHED)

**Books or other non-periodical, one-time publications.**

Nothing to Report

**her publications, conference papers and presentations.**

Effectively Addressing Challenges for Successful Implementation of Healthcare Delivery Using Clinical Video Technology (CVT) at a VA SCI/D Center - HSRD/QUERI National Conference 2019

• **Website(s) or other Internet site(s)**

Nothing to report

• **Technologies or techniques**

Nothing to report

• **Inventions, patent applications, and/or licenses**

Nothing to report

- **Other Products**

Virtual Technology Data Codebook

## 7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

### What individuals have worked on the project?

**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:** Co-Investigator  
**Nearest person month worked:** 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:** 8 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?**

Nothing to report

**What other organizations were involved as partners?**

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

**QUAD CHART:** updated and submitted

**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.*

Data Codebook, Summary presentation to Veterans- Caregivers Advisory Board, Published manuscript.