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**TITLE:** Promoting Healthy Caregiving: Digitalized Education and Support for Family Caregivers

**PRINCIPAL INVESTIGATOR:** Dr. Carol Gibson-Gill, M.D.

**CONTRACTING ORGANIZATION:** Veterans Affairs New Jersey Healthcare System  
East Orange, NJ

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Promoting Healthy Caregiving: Digitalized Education and Support for Family Caregivers

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**13. SUPPLEMENTARY NOTES**

**14. ABSTRACT**

The proposed project will leverage the research team's experience delivering a successful hospital-based caregiver education program, mixed-methods research expertise, and recent innovations in online education technology to create an easily accessible, highly scalable, dynamic web-based program for family Caregivers of Veterans with SCI.

The proposed project is still in the development and administrative stages. The project will use a mixture of qualitative and quantitative data collection to create a web-based education program that is rooted in the experiences of three key stakeholder groups: family Caregivers of Veterans with SCI, Veterans with SCI, and SCI professionals. The program will complement existing Veterans Health Administration's (VHA) caregiver resources by giving special attention to family Caregivers' needs and concerns related to functional, medical, and psychosocial challenges created by SCI. In Phase 1 of the project, a curriculum for the program will be developed based on data obtained from focus groups with key stakeholders (50 family Caregivers, 10 Veterans, 10 SCI professionals), who will identify learning needs and recommend content for the proposed web-based program. In Phase 2, the team will develop multimedia content for the program, with technical assistance from the Employee Education Services Department of the VA, ongoing feedback from a Community Advisory Board, and input from a focus group of stakeholders who will review the complete program prior to pilot testing. In Phase 3, the program will be pilot tested with 25 SCI family Caregivers, who will complete questionnaires and cognitive interviews to provide detailed data on perceptions of program content and format, as well as recommended changes. Additional feedback will be obtained from interviews with 5 Veterans with SCI and 5 SCI professionals who are naïve to the program. Revisions will be made to the program mid-way through and after completion of pilot testing to create a program ready for widespread use.

The proposed project addresses the focus area of psychosocial issues relevant to SCI in individuals with SCI and their caregivers by creating a web-based education program designed to enhance the knowledge base and well-being of family caregivers. The web-based program will provide Caregivers with timely, flexible and affordable access to education on topics of interest to them. The program can complement existing facility-based programs, and enhance the capacity of military, Veteran, and civilian programs to meet the needs of family Caregivers in the community. In addition, the project will provide data on learning needs and preferences that can assist ongoing efforts to optimize Caregiver education.

**15. SUBJECT TERMS**

None listed.

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**1. INTRODUCTION:**

Family Caregivers play a key role in enabling Veterans with SCI to live healthy, productive lives in the community. Caregivers of Veterans with SCI experience considerable burden and distress, leading to poor health and reduced quality of life for both Caregivers and Veterans with SCI. There is a paucity of easily accessible resources focused on helping Caregivers of people (civilians and Veterans) with SCI care for themselves while providing care to their loved ones, with limited educational resources for SCI Caregivers that are informed by the experiences of the Caregivers themselves. The proposed project will create a learner-driven, highly flexible, online education program to help VA and other health care systems promote health and well-being among family Caregivers of Veterans with SCI.

**2. KEYWORDS:**

Spinal cord injury, caregivers, Veterans, educational program, online

**3. ACCOMPLISHMENTS:**

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

SOW Task	Timeline for completion	Progress
<b>Major Task 1: Preparing to launch study</b>		
Research team and V-CAB study kick-off and planning meeting	Y1Q1	Completed
Submit for WOC	Y1Q1	75%
Finalize consent form & human subjects' protocol	Y1Q1	Completed
Submit to VANJHCS IRB application	Y1Q1	Completed
Submit for Military 2 <sup>nd</sup> level IRB review (ORP/HRPO)	Y1Q1-Q2	Completed
Submit VA Intellectual Property Agreement	Y1Q1-Q2	Deferred
Initiate staff training	Y1Q1-Q2	Completed
Milestone Achieved: Local IRB/IACUC Approval	Y1Q1-Q2	Completed
Milestone Achieved: HRPO/ACURO Approval	Y1Q1-Q2	Completed
<b>Aim 1. Identify program content considered valuable by key stakeholders, including family Caregivers, veterans with SCI, and SCI professionals.</b>		
<b>Major Task 2: Conduct Focus Groups at VANJHCS</b>		
Research team weekly meetings to address study management, procedures, and logistics	Y1Q1-Q4	On Going
Meet with V-CAB to review study recruitment and focus group instruments	Y1Q3	On Going
Recruit and consent <b>(50) SCI Veteran family Caregivers</b> to participate in focus groups to provide a spectrum of experiences and challenges faced to adjust to their new role and as the needs of their loved one evolve over time.	Y1Q3-Y2Q1	In Progress

<i>Conduct (7) Focus Groups with (50) VANJHCS SCI Veteran family caregivers</i>	Y1Q3-Y2Q1	Pending
Recruit and consent <b>(10) SCI Veterans</b> to participate in focus groups to provide a spectrum of experiences and challenges faced to adjust to their new role and as the needs of their loved one evolve over time.	Y1Q3-Y2Q1	Pending
<i>Conduct (7) Focus Groups with (10) VANJHCS Veterans</i>	Y1Q3-Y2Q1	Pending
Recruit and consent <b>(10) SCI Healthcare Professionals</b> to participate in focus groups to provide a spectrum of experiences and challenges faced to adjust to their new role and as the needs of their loved one evolve over time.	Y1Q3-Y2Q1	Pending
<i>Conduct (7) Focus Groups with (10) VANJHCS SCI Healthcare Professionals</i>	Y1Q3-Y2Q1	Pending
Conduct qualitative data analyses from focus group data collection	Y1Q3-Y2Q2	Will be completed by end of Y2Q2
<i>Milestone Achieved: Conduct seven focus groups with SCI Veterans, SCI Family Caregivers, and VANJHCS SCI Healthcare Professionals</i>	Y2Q1	Pending
<i>Milestone Achieved: Aim I of study completed</i>	Y1Q3-Y2Q2	Will be completed by end of Y2Q2

### What was accomplished under these goals?

#### Major Activity for Quarter #1-2: Preparing to launch study (Months 1-6)

##### *Significant Results or Key Outcomes:*

- The research team has created a schedule for weekly research team meetings to address study management, execution of the study procedures, and to work on the IRB and HRPO submission.
- WOC status has been obtained for the Research Coordinator and Dr. Denise Fyffe.
- The local VANJHCS IRB exempted the research study: *“Promoting Healthy Caregiving: Digitalized Education and Support for Family Caregivers”* on November 25, 2020.
- We have recruited, hired, and trained the study’s Research Coordinator. She has been involved in the submission of the IRB and the HPRO application.
- Veterans and Caregivers to be part of the VCAB were identified and invited to the research team. On March 8, 2021, the study kick-off meeting with the VCAB was held. The purpose of the meeting was to explain the project objectives and the role of the VCAB members. During the meeting, all the VCAB members expressed their interest in participating in the project. They expressed no concerns re: the project timeline and progress made so far.
- The Office of Research Protections (ORP) Human Research Protection Office (HRPO) approval was received on February 24, 2021.
- The project remains under the purview of the VA Research and Development (R&D) as it is IRB exempt. The research team answered reviewers’ questions and comments. R&D approval was obtained on March 1, 2021.
- The Principal Investigator, Dr. Carol Gibson-Gill, worked with U.S. Department of Veterans Affairs Technology Transfer Program to develop a VA Intellectual Property Agreement. She was informed by them that the VA currently does not have a system to create Intellectual Property Agreement, but it is being worked on at a national level. They informed Dr. Gibson-Gill that it is premature for an Intellectual

Property Agreement since the product has not been created and when it is created, we can have our collaborating partner, Kessler Foundation, start this process (if by then, the VHA does not have its own process in place). He also recommended that once this process is started by Kessler Foundation, we should notify his office so they can work alongside Kessler Foundation and if the VA's process for creating an Intellectual Property Agreement is set up before this time, he will notify the PI.

- The research team identified and secured a transcription services company.

#### Major Activity for Quarter #3-4: Preparing to launch study (Months 6-12)

##### *Significant Results or Key Outcomes:*

- The research team continues to have weekly meetings to address study management, execution of the study procedures, develop study tools, and how-to logistics.
- We developed demographic questionnaire packets for the Veteran and Caregiver participants. Each questionnaire was reviewed twice by the research team before being presented to members of the VCAB.
- From May 11-May 19, 2021, Drs. Fyffe and Zanca conducted one-on-one interviews with 4 members of the VCAB. The purpose of these interviews was to review and receive feedback for the demographic questionnaire packets with these VCAB members.
- We have generated a list of Family Caregivers for recruitment purposes.
- We provided in-service to the SCI/D department to introduce the study, which would help with recruitment.
- Potential focus group questions for Veterans and Caregivers were identified, and draft focus group scripts were developed.
- On August 16, 2021, the research team held a meeting with VCAB members to review and receive feedback for the Caregiver focus group script.
- The recruitment letter and flyer were created and are ready for dissemination.
- Dr. Jeanne Zanca has finalized the WOC process and is currently waiting for approval.
- The research team has established contact with the transcription services company and has received a quote for future services.
- Due to unforeseen circumstances, there were staff changes. The research team has found a candidate to fill the Research Assistant position. The new Research Assistant is in the final stages of onboarding.

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

Nothing to report.

#### **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?**

During the next reporting period, we plan to accomplish the following goals:

- Continue weekly Research team meetings to address study management, procedures, and logistics.
- Complete the training of the new Research Assistant.
- The research team, in collaboration with the VCAB, will develop and finalize the focus group scripts for the SCI professionals.
- Recruit and consent participants for Phase 1 [content identification]: *(50) SCI Veteran family Caregivers, (10) SCI Veterans, (10) SCI Healthcare Professionals* to participate in the focus groups.
- Complete the Focus groups as per the SOW.
- Dr. Zanca's WOC status will be finalized.

**4. IMPACT:**

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

The findings will enhance the capacity of the VA SCI facilities to address the educational needs of Family Caregivers of Veterans with SCI.

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

Nothing to report.

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

Nothing to report.

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

The findings will advance SCI care by offering solutions to problems SCI Caregivers face when providing care to their Veterans' loved ones after they are discharged to home post- acute SCI rehabilitation.

**5. CHANGES/PROBLEMS:**

**Changes in approach and reasons for change**

Nothing to Report.

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

Due to emergency family health issues, the initial Research Coordinator had to resign from her position. Her last day was March 23, 2021. The current Research Coordinator, Tatiyanna Mingo, transitioned into the role of Research Coordinator from Assistant effective May 17, 2021. At this time, the team has identified, interviewed, and selected a candidate to fill the Research Assistant position. Though she is in the final stages of the onboarding process, the process has been somewhat delayed.

The ongoing COVID-19 pandemic could potentially create delays in recruitment. To prevent delays in study recruitment, while VANJHCS has processes in place to help mitigate the COVID-19 pandemic (via telephone, videoconferencing and in-person, as applicable).

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

At this time, the team has identified, interviewed, and selected a candidate to fill the Research Assistant position.

**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:**

- **Publications, conference papers, and presentations**

**Journal publications.**

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

Nothing to report.

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

Nothing to report.

- **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**

Nothing to report.

## 7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Personnel	Role	Nearest person month worked	Contribution to the project
<b>VA New Jersey Healthcare System</b>			
Carol Gibson-Gill, MD	Principal Investigator	6	<ul style="list-style-type: none"> <li>• participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>• aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>• assisted with the coordination of the VCAB meeting to review the Caregiver focus group script.</li> <li>• supervised the Research Coordinator.</li> <li>• interviewed and hired the new Research Assistant.</li> <li>• collaborated on the WOC process for Dr. Zanca.</li> <li>• aided in the creation of the recruitment letter and flyer for dissemination.</li> </ul>

Joyce Williams, LCSW	Co- Principal Investigator	6	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>assisted with the coordination of the VCAB meeting to review the Caregiver focus group script.</li> <li>collaborated on the WOC process for Dr. Zanca.</li> <li>supervised the Research Coordinator.</li> <li>interviewed and hired the new Research Assistant.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> <li>generated a list of Family Caregivers for recruitment.</li> </ul>
Jeanne Zanca, PhD, MPT	Co- Investigator	3.5	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>helped facilitate the VCAB meeting to review the Caregiver focus group script.</li> <li>finalized the WOC process.</li> <li>assisted in creating the recruitment letter and flyer for dissemination.</li> </ul>
Denise Fyffe, PhD	Co- Investigator	3.5	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>facilitated the VCAB meeting to review the Caregiver focus group script.</li> <li>interviewed and hired the new Research Assistant.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> </ul>
Tomicka McMillion, RN, DNP	Co- Investigator	3.5	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>assisted with the coordination of the VCAB meeting to review the Caregiver focus group</li> </ul>

			<ul style="list-style-type: none"> <li>script.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> <li>generated a list of Family Caregivers for recruitment.</li> </ul>
Jazmin Torres, BSN, RN	Co-Investigator	3.5	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>assisted with the coordination of the VCAB meeting to review the Caregiver focus group script.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> <li>generated a list of Family Caregivers for recruitment.</li> </ul>
Mary Ann Rosenburg, RN, BSN	Co-Investigator	3.5	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> <li>generated a list of Family Caregivers for recruitment.</li> </ul>
Tatiyanna Mingo, MPH	Research Coordinator	6	<ul style="list-style-type: none"> <li>participated in weekly collaborative team research to address study management, procedures, and logistics.</li> <li>aided in the development of the Veteran and Caregiver focus group scripts.</li> <li>scheduled and coordinated the VCAB meeting to review the Caregiver focus group script.</li> <li>assisted in drafting the recruitment letter and flyer for dissemination.</li> <li>coordinated interview for prospective Research Assistant.</li> <li>established contact with transcription services and received a quote for future work.</li> </ul>

**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

Location of Organization: West Orange, New Jersey

Partner's contribution to the project

- 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)

On behalf of the Kessler Foundation, Dr. Denise Thomas-Fyffe and Dr. Jeanne Zanca, are collaborating on this project as Co-Investigators. Drs. Fyffe and Zanca will at times interview participants on the VANJHCS campus.

## **8. SPECIAL REPORTING REQUIREMENTS**

**COLLABORATIVE AWARDS:**

**QUAD CHARTS:**

## **9. APPENDICES:**