

AWARD NUMBER: W81XWH-20-1-0383

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

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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 (family Caregivers, Veterans, and 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 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 Veterans with SCI and 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

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
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TABLE OF CONTENTS

	<u>Page</u>
1. Introduction	5
2. Keywords	5
3. Accomplishments	5
4. Impact	9
5. Changes/Problems	10
6. Products	11
7. Participants & Other Collaborating Organizations	12
8. Special Reporting Requirements	14
9. Appendices	14

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

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

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

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.

Major Task 2: Conduct Focus Groups at VANJHCS	Timeline for Completion	Progress
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 (50) SCI Veteran family Caregivers 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	Completed
<i>Conduct (7) Focus Groups with (50) VANJHCS SCI Veteran family caregivers</i>	Y1Q3- Y2Q1	Completed
Recruit and consent (10) SCI Veterans 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	Completed
<i>Conduct (7) Focus Groups with (10) VANJHCS Veterans</i>	Y1Q3- Y2Q1	Completed
Recruit and consent (10) SCI Healthcare Professionals 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	Completed

<i>Conduct (7) Focus Groups with (10) VANJHCS SCI Healthcare Professionals</i>	Y1Q3- Y2Q1	Completed
Conduct qualitative data analyses from focus group data collection	Y1Q3- Y2Q2	In Progress
<i>Milestone Achieved: Conduct seven focus groups with SCI Veterans, SCI Family Caregivers, and VANJHCS SCI Healthcare Professionals</i>	Y2Q1	Completed
<i>Milestone Achieved: Aim I of study completed</i>	Y1Q3- Y2Q2	In Progress
<i>Aim 2. Develop engaging, multimedia content to address priority content areas, involving key stakeholders in the process.</i>		
Major Task 3: Program Creation-Multimedia Content Development		
Research team partner with VHA's Employee Education Services (EES) department, to create online education content targeted to veterans and Caregivers.	Y2Q1-Q4	In Progress
Research Team participate in Platform training for online program development and presentation	Y2Q2	In Progress
Create Web-based ART Healthy Caregiving online program	Y2Q2-Q4	In Progress
<i>Milestone Achieved: Development of web- based ART Healthy Caregiving online program</i>	Y2Q4	In Progress
<i>Milestone Achieved: Aim II of study completed</i>	Y2Q4	
<i>Aim 3. Test the web-based program with end users (family Caregivers) to assess usability and use feedback from this process to produce a final version of the course that is ready for large-scale use.</i>		

What was accomplished under these goals?

Major Activity for Year 2 Quarter #1

Significant Results or Key Outcomes:

- The research team continued to have weekly meetings to address study management, execution of the study procedures, develop study tools, and how-to logistics.
- Focus Group scripts were finalized for Veteran, Caregiver, and SCI Healthcare professional participants.
- Each study measure and tool (i.e., focus group scripts and demographic questionnaires) was reviewed and approved by the Research and Development (R&D) committee.
- Due to unforeseen circumstances, there were staff changes. The research team hired a new Research Assistant who has been trained.
- The research team initiated recruitment and consenting of participants for Phase 1 [content identification] and focus groups began.
- The team recruited, consented, and conducted focus groups for 49% of expected family Caregivers.
- Focus groups for Veteran participants were completed.
- Focus groups for SCI Healthcare Professionals were completed.
- The team conducted 2 Caregiver focus groups, 1 Veteran focus group, and 2 SCI Healthcare Professional focus groups.
- The research team established contact with the transcription services company (VHA Salt Lake City Centralized Transcription Services Program), enabled them access to the completed focus groups' audio, and we were added to the transcription company's queue of customers requiring transcripts done.
- Participant demographic questionnaires were entered into REDCap in preparation of data analysis.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 2 Quarter #2

Significant Results or Key Outcomes:

- The research team continued to have weekly meetings to address study management, execution of the study procedures, develop study tools, and how-to logistics.
- During this quarter, we conducted 3 Caregiver focus groups and 1 individual Caregiver interview. Our target goal for Aim 1 recruitment was 35-56 participants, with no more than 70.
- Research Team met with VHA's Employee Education Services to begin online program development.
- Platform training for online program development and presentation began.
- The transcription company began transcribing audio files. There was a delay due to the transcription company's backlog.
- The team began reviewing the audio files for a preliminary analysis of common themes and topics.
- Participant demographic questionnaires were entered into REDCap in preparation of data analysis.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 2 Quarter #3

Significant Results or Key Outcomes:

- The research team continued to have weekly meetings to address study management, execution of the study procedures, develop study tools, and how-to logistics.
- During this quarter, we conducted 2 Caregiver focus groups and 3 individual Caregiver interviews, with a total of 24 Caregiver participants.
- The transcription company, CTSP was in the process of transcribing audio files. There is a delay due to the transcription company's backlog.
- Transcripts received from CTSP were in the process of quality checks.
- The team began reviewing the audio files for a preliminary analysis of common themes and topics for the development of program content.
- Platform training for online program development and presentation began.
- The research team met with EES (Employee Education System) to discuss project outcomes to date and to set-up a process of collaboration for the production of program content and videos.
- Participant demographic questionnaires were entered into REDCap in preparation for data analysis.
- On June 17, 2022, the research coordinator presented the Digitalized project and its current status to the VANJHCS SCI/D department.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 2 Quarter #4

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.
- The research team has been assigned a Project Manager and an Executive Producer by the VHA's EES in preparation of the development of the online education program.
- The team met with the Project Manager and Executive Producer to discuss preliminary research findings, including the topics and themes derived from the focus groups.
- Focus Group audio was transcribed by the VHA Salt Lake City Centralized Transcription Services Program. As of September 22, 2022, all audio for phase 1 have been transcribed.
- Quality checks of focus group transcripts continue.
- The research team has developed a preliminary list of topics and themes for the online content. From that, the team is developing scripts for the online program videos.

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

- Electronic Documentation of Written Informed Consent hosted by ORPP&E Webinars (10/14/2021)
- Research Assistant Orientation by SCI/D research team (11/15/2021, 11/16/2021, 11/18/2021)
- VAIRRS Monthly Webinar hosted by ORPP&E Webinars (01/31/2022)
- Technical Assistance Webinar for Spring 2022 – Quality of Life Grants – Direct Effect and Expanded Impact (02/02/2022)
- Basic Research and Preparation (and a bit more) with the SAS Grid hosted by Robert Auffrey (06/09/2022)
- The APPROACH Study: Assessing Pain, Patient Reported Outcomes and Complementary and Integrative Health hosted by HSR&D Cyberseminars (09/15/2022)
- IRBNet Basics for Investigators hosted by Veteran Affairs (09/20/2022)

How were the results disseminated to communities of interest?

The research coordinator presented an update of the study to the SCI/D department on 06/17/2022. The team was also accepted to the ACRM symposium “Understanding and Supporting Family Caregivers Needs and Skills for Civilians and Veterans with SCI.” The team will present on November 10th 2022.

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

- Finish quality checks of transcripts.
- Finish data analysis of themes and topics collected during focus groups.
- Conduct a VCAB meeting to review on going progress.
- Develop online program in collaboration with EES.
- Recruit and consent Volunteers (SCI Veterans, family caregivers & Healthcare Professionals to participate in the pre-piloting review process.
- Conduct Pre-Piloting Review with Volunteers.
- Recruit and consent groups of Family Caregivers to participate in the Pilot-Testing with Caregiver End-User process.
- Conduct Pilot Testing with groups of Family Caregivers.
- Recruit and consent SCI Veterans and SCI Healthcare Professionals to participate in the Stakeholders Program Review to evaluate program content and provide feedback via survey
- Conduct Stakeholders Program Review with SCI Veterans & SCI Healthcare Professionals.
- V-CAB Review of final pilot of online program.

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?

Nothing to Report

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 Caregivers who participated in focus groups formed connections and spoke of connecting outside of the group to support each other.

- 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

Nothing to Report

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

During this period, the team finalized onboarding and training of the new Research Assistant, Nemy Thomas. Due to changes in the PIV process, there were delays in getting Ms. Thomas a PIV card, and subsequently delays in receiving VA equipment. The VA granted her exemption at this time to work on her personal computer.

The transcription company was delayed until September 2022 in transcribing audio files due to the company's backlog. As a result, complete data analysis has also been delayed.

Dr. Gibson-Gill was informed that the VA currently does not have a system to create Intellectual Property Agreement. VA Central Office has recommended that we start the process within our partner institution Kessler Foundation when the research study has reached that point.

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

N/a

Significant changes in use or care of human subject

Nothing to Report

Significant changes in use of biohazards and/or select agents

n/a

6. PRODUCTS:

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

The Research Coordinator presented an update of the study to the SCI/D department on 06/17/2022. Please see attachments for presentation.

Journal publications.

Nothing to Report

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

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?

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”.

Personnel	Role	Nearest person month worked	Contribution to the project
VA New Jersey Healthcare System			
Carol Gibson-Gill, MD	Principal Investigator	6	No change
Joyce Williams, LCSW	Co- Principal Investigator	6	No change
Jeanne Zanca, PhD, MPT	Co- Investigator	3.5	No change
Denise Fyffe, PhD	Co- Investigator	3.5	No change

Erik Wallen, PhD	Co- Investigator	3.5	<ul style="list-style-type: none"> participated in weekly collaborative team research to address study management, procedures, and logistics. acted as the point of contact for the research team with the EES. developed preliminary themes and topics for program content.
Tomicka McMillion, RN, DNP	Co- Investigator	3.5	No change
Jazmin Torres, BSN, RN	Co- Investigator	3.5	No change
MaryAnn Rosenburg, RN, BSN	Co- Investigator	3.5	No change
Tatiana Mingo, MPH	Research Coordinator	6	No change
Nemy Thomas, BA	Research Assistant	3.5	<ul style="list-style-type: none"> participated in weekly collaborative team research to address study management, procedures, and logistics. administered demographic questionnaires to study participants. coordinated and scheduled participant focus groups. entered Caregiver demographic questionnaires into REDCap in preparation of data analysis. developed preliminary themes and topics for program content.

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: *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://ebrap.org/eBRAP/public/index.htm> for each unique award.*

QUAD CHARTS: *If applicable, the Quad Chart (available on <https://www.usamraa.army.mil/Pages/Resources.aspx>) 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.*

Appendices A: The Research Coordinator presented an update of the study to the SCI/D department on 06/17/2022. Please see attachments for presentation.