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

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CONTRACTING ORGANIZATION: VA New Jersey Health Care System, East Orange, NJ

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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.

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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?

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	Completed
<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	Completed
<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>		
Major Task 4: Online Program Evaluation- testing with end users (family caregivers) to assess usability, and gain feedback		
Recruit and consent (10) Volunteers (SCI Veterans, family caregivers & Healthcare Professionals) to participate in the pre-piloting review process (NOTE: This review board will be a blended group of 10 volunteers, and it will not be affiliated with the V-CAB)	Y2Q4- Y3Q1	
Conduct Pre-Piloting Review with (10) Volunteers	Y2Q4- Y3Q1	
Recruit and consent (5) Groups of 10 Family Caregivers to participate in the Pilot-Testing with Caregiver End-User process.	Y3Q1-Q2	
Conduct Pilot Testing with (5) groups of 10 Family Caregivers	Y3Q1-Q2	
Recruit and consent (5) SCI Veterans and (5) SCI Healthcare Professionals to participate in the Constituents Program Review to evaluate program content and provide feedback via survey	Y3Q 1-Q2	
Conduct Constituents Program Review with (5) SCI Veterans & (5) SCI Healthcare Professionals.	Y3Q2	
V-CAB Review of final pilot of online program	Y3Q3	
<i>Milestone Achieved: Conduct Pre-piloting Review, Pilot- Testing, & Constituents Program Review with SCI Veterans, SCI Family Caregivers, and VANJHCS SCI Healthcare Professionals to evaluate online program.</i>	Y3Q3	
<i>Milestone Achieved: Aim III of study completed</i>	Y3Q3	
Major Task 5: Online Program Dissemination and publications		
Disseminate findings at national professional meetings (e.g., abstracts, presentation, publications)	Y3Q3-Q4	On going
<i>Milestones Achieved: Analyses completed; Findings disseminated at professional meetings and publications</i>	Y3Q4	

What was accomplished under these goals?

Major Activity for Year 3 Quarter #1: Program Creation-Multimedia Content Development (Months 1-3)

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.
- Transcripts were completed and quality checks of the focus groups transcripts have also been completed.
- The team reviewed the audio files for a preliminary analysis of common themes and topics for the development of program content.
- The research team presented Employee Educational System (EES) with topics and themes culminated from the preliminary analysis.
- The team began outlining and creating video scripts for the development of program content.
- We began identifying potential Caregiver interviewees to be included in the online program.
- Platform training for online program development and presentation was completed.
- The research team continued to meet with EES to discuss project outcomes to date and to set-up a process of collaboration for the production of program content and videos.
- The team's presentation was accepted to the American Congress of Rehabilitation Medicine (ACRM) symposium and presented on November 10th, 2022. The presentation was called "Understanding and Supporting Family Caregivers Needs and Skills for Civilians and Veterans with SCI". Please see attachment A for presentation.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 3 Quarter #2: Program Creation-Multimedia Content Development (Months 3-6)

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.
- We developed a preliminary outline and script for the program content.
- The team developed a supplemental document to be included in the program. This document will be a guide of the different disciplines encompassing the Health Care Team, a brief description of their roles, and potential questions Caregivers may ask them.
- The team developed a list of dialogue and interview questions to provide to the video team for filming.
- The team was invited to make a presentation to the American Congress of Rehabilitation Medicine (ACRM) symposium on March 15, 2023. The presentation is called "Understanding and Addressing Self-Care Needs of Family Caregivers of Veterans with SCI." Please see attachment B for presentation.
- The research team continued to meet with EES to discuss project outcomes to date and to set-up a process of collaboration for the production of program content and videos.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 3 Quarter #3: Program Creation-Multimedia Content Development (Months 6-9)

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.
- The research team developed a course grid for the videos to be included in the program content, which the educational videos will be built upon.
- We continued to meet with EES to discuss content goals and videos.
- The team was invited to present some of the preliminary findings at American Congress of Rehabilitation Medicine conference in November 2023. The presentation title is “Understanding and Addressing Self-Care Needs of Family Caregivers of Veterans with SCI.” Please see attachment (B) for presentation.
- Mrs. MaryAnn Rosenburg completed the process of becoming a Worker without Compensation (WOC) to continue working on the study after retiring from a full time VA position.
- The research team continued to participate in ongoing educational trainings.

Major Activity for Year 3 Quarter #4: Program Creation-Multimedia Content Development (Months 9-12)

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.
- On July 17th, 2023, the research team updated the VCAB members on study progress and presented to them the list of interview questions for program content for members to review. Feedback from the meeting was used to refine the list of questions. Please see attachment (C) for the VCAB meeting presentation and attachment (D) for list of interview questions.
- Veterans and Caregivers were identified to be interviewed for the Digitalized program content.
- The team is in the last stages of editing the Digitalized Course Grid and has submitted current draft to EES. The course grid will inform both the audio and visual aspects of filming. Please see attachment (E) for course grid.
- We continue to meet with EES to discuss program content and goals.
- The team began planning filming logistics with our Employee Educational System (EES) representative.
- The team requested and the study was granted a no-cost extension year on September 11, 2023. The new approved study end date is August 31, 2024.
- The research team continues to participate in ongoing educational trainings.

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

- ORO - CPR Review POWER HOUR (10/27/2023)
- HSR&D Cyberseminars: Racial and Ethnic Differences in the Prescription of SGLT2 Inhibitors and GLP1 Receptor Agonists Among Patients (01/11/2023)
- ORD Qualtrics Onboarding (03/17/2023)
- VIREC Database and Methods Seminar: Assessing Race and Ethnicity in VA Data (4/3/2023)

How were the results disseminated to communities of interest?

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 presented on November 10th 2022.

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

- Conduct a VCAB meeting to review on going progress.
- Finalize online program in collaboration with EES for pilot testing.
- Begin filming program content (completing Major Task 3).
- Recruit Volunteers (SCI Veterans, family caregivers & Healthcare Professionals) to participate in the pre-piloting review process.
- Recruit groups of Family Caregivers to participate in the Pilot-Testing with Caregiver End-User process.
- Recruit SCI Veterans and SCI Healthcare Professionals to participate in the Stakeholders Program review to evaluate program content and provide feedback via survey.

4. IMPACT:

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:

Changes in approach and reasons for change

Nothing to Report.

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

The Research Assistant, Nemy Thomas, resigned from her position on March 9, 2023 to make a career change. Team will initiate the replacement process.

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.

Changes that had a significant impact on expenditures

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 team presented at the ACRM symposium on November 10th 2022. The presentation was called “Understanding and Supporting Family Caregivers Needs and Skills for Civilians and Veterans with SCI.” Please see attachment (A) for presentation.
- On July 17th, 2023, the research team updated the VCAB members on study progress and presented to them the list of interview questions for program content for members to review. Feedback from the meeting was used to refine the list of questions. Please see attachment (C) for the VCAB meeting presentation and attachment (D) for list of interview questions.

Journal publications.

Nothing to Report

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

Nothing to Report

Other publications, conference papers and presentations.

“Understanding and Supporting Family Caregivers Needs and Skills for Civilians and Veterans with SCI” at ACRM symposium (11/10/2022)

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
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	No change
Tomicka McMillion, RN, DNP	Co- Investigator	3.5	No change
Jazmin Torres, BSN, RN	Co- Investigator	3.5	No change
MaryAnn Rosenberg, RN, BSN	Co- Investigator	3.5	No change
Tatiana Mingo, MPH	Research Coordinator	6	No change

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:

Appendix (A): "Understanding and Supporting Family Caregivers Needs and Skills for Civilians and Veterans with SCI" 2022 ACRM presentation.

Appendix (B): Understanding and Addressing Self-Care Needs of Family Caregivers of Veterans with SCI" ACRM 2023 presentation.

Appendix (C): VCAB presentation

Appendix (D): List of interview questions to provide to EES

Appendix (E): Digitalized Course Grid to date