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AWARD NUMBER:

TITLE: Veterans with Gulf War Illness: Understanding the Spectrum of Experiences Related to Aging and Demographics

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RECIPIENT: Drexel University

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14. ABSTRACT

Many veterans who served in the 1990-91 Gulf War developed chronic symptoms that could not be explained by established medical diagnoses or standard laboratory tests. These included physical symptoms like widespread pain, muscle aches, headaches, persistent problems with memory and thinking, fatigue, breathing problems, digestive problems, and, skin abnormalities. Accompanying these physical challenges were changes in behavior and challenges in interpersonal relationships. The cluster of symptoms is referred to as Gulf War Illness (GWI) and is estimated to have affected 175,000 to 250,000 of the nearly 700,000 troops deployed to the Gulf War. Despite being over two decades out since the war, there have been no studies to date that focus on the individual and unique experiences of veterans with GWI including their perceptions of the impact of the illness, differences in experiences related to aspects like aging and gender, quality of care received, barriers faced, and, the related impact on interpersonal relationships, and, quality of life. The main research questions for the study are as follows: What are the perceptions and experiences of veterans with GWI regarding symptoms of physical health, cognitive functioning, quality of life as well as the quality of care they receive? In addition, the study will explore experiences related to the natural process of aging; differences in experiences across demographic characteristics (e.g. gender, race/ ethnicity, type of exposure etc.) as well as capture the perceptions and experiences of healthcare providers who serve Veterans with GWI. Data for the study will include narrative interviews as well as collage self-portraits of Veterans’ experiences of living with GWI. This research will lead to the development of an educational curriculum for healthcare providers, namely, a Massive Online Open Access Course (MOOC) that will include recent research on GWI and qualitative perspectives from a range of Veterans living with the illness. The timeline for the study is three years. Years one and two involve data collection in the form of interviews with Veterans and healthcare providers and analyses of these data. Year three will be focused on the development of the MOOC curriculum based on findings from the study. Given that there is significant concern that the needs of this population have not been adequately served, the findings could help educate healthcare providers through the voices and portraits of Veterans with GWI. This in turn could help advance the mission to provide personalized care to patients with GWI and integrate them more effectively into the healthcare provided through the VA, DoD and other federal agencies.

15. SUBJECT TERMS

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

This systematic qualitative research project seeks to learn about the individual and unique experiences of Veterans with Gulf War Illness (GWI) including perceptions of the impact of their illness, quality of care, barriers faced, and impact on interpersonal relationships and quality of life (Aim 1). The differences in experiences across demographic characteristics such as gender, race/ethnicity, and type of exposure, as well as experiences related to aging are of particular interest. Furthermore, perceptions and experiences of health care providers of Veterans with GWI were gathered (Aim 2). The final aim (Aim 3) is to prepare an up-to-date curriculum that can be presented through a massive open online course. Overall, 40 Veterans and 10 health care providers will be interviewed. Collage portraits of experiences with GWI will also be collected from Veterans.

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

Gulf War Illness, Veteran experiences, Health care provider experiences, Qualitative Study, Grounded Theory, Perceptions, Barriers, Collage portraits

3. **ACCOMPLISHMENTS:** The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer 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.

MONTHS	MAIN PROJECT MILESTONES <u>SPECIFIC AIM 1 & AIM 2</u>	ACCOMPLISHED
	Task 1: Hiring, regulatory compliance, and reporting	
1 – 3	Develop job description, hire project coordinator	yes
1 – 6	Coordinate with DU for material transfer agreements	yes
1 – 3	Submit IRB documents for Aim 1 and Aim 2	yes
Annual	Coordinate with sites for annual IRB report	yes
4 – 6	Receive IRB approval through CTVHCS and DU	yes
3 – 6	Visit CoE to train data collector in interview protocol	yes
3 – 6	Schedule weekly e-mail check-ins and monthly conference calls	yes
6	Train research staff	yes
	Task 2: Recruit and enroll Veterans and begin data collection	
6 – 8	Review literature and summarize demographics	yes
4 – 6	Conduct 2 interviews with PC and PI to ensure consistency	yes
4 – 6	First two veterans with GWI consented, screened and enrolled in study	yes
4 – 6	Complete transcription of the first two Veteran interviews	yes

MONTHS	MAIN PROJECT MILESTONES	ACCOMPLISHED
4 – 6	Set up of de-identified database on Dedoose	yes
4 – 8	Begin recruitment of healthcare providers (HCP)	yes
4 – 8	Conduct first interviews with healthcare provider	yes
4 – 8	Complete transcription of the first interview of healthcare provider	yes
5 – 7	First healthcare provider consented, screened and enrolled First transcript transcribed and entered into database	yes yes
Task 3: Continue data collection and data analysis		
6 – 23	Continued data collection for Aim 1 (veteran experiences)	35% complete
	Continued data collection for Aim 2 (HCP experiences)	yes
8 – 24	Continue additions to de-identified database for both aims	yes
8 – 24	Continue to upload de-identified transcripts and images	yes
8 – 24	Refine coding scheme and begin coding	yes
12 – 24	Review coding and analysis with secondary coder	Veteran data: no Health care providers: yes
14 – 24	Complete axial and selective coding	Veteran data: no Health care providers: yes
18 – 24	Identify themes and grounded theory framework; review findings with research team	Veteran data: no Health care providers: yes
SPECIFIC AIM 3		
Task 4: Create MOOC, disseminate findings and prepare final reports		
24 – 25	Create template for unit readings, course content, etc.	yes
24 – 25	Coordinate subject matter experts to create curriculum Units including course content, lectures, PowerPoint Slides, assignments and assessments	yes
24 – 30	Create unit with lay summaries, Veterans' perspectives and art work on experiences with GWI	yes
25 – 30	Create course content and review for consistency; ensure that the literature is current and includes most recent research on GWI; gather feedback	75%
33 – 36	Complete the MOOC course content and curriculum and submit to funder	no
33 – 36	Submit manuscripts for dissemination and prepare final reports for project	1 manuscript submitted

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.

1. Major activities:

The major activities during this reporting period included conducting a grounded theory study to gather the perspectives of health care providers serving Veterans with GWI and to develop the content for a MOOC as well transferring the subcontract to a new site.

2. Specific objectives

The specific objectives during this reporting period included (1) Recruiting and enrolling of health care providers, interviews, data collection, and data analysis (2) Submitting a manuscript for dissemination of results, (3) creating units for MOOC and (4) Closing out parts of the study that were completed including at the original part site of CoE, VISN 17 in Waco, TX.

3. Significant results/key outcomes

A grounded theory model for health care providers of Veterans with GWI was developed and a manuscript on this work is under review. Findings were also accepted to three conferences. The process for moving the sub award to a new site is completed and we aim to submit the IRB for this part of the project to HRPO soon.

4. Other achievements

n/a

5. Goals not met

Data collection and analysis of Veteran’s interviews. During this reporting period the main challenge was the public health emergency due to the coronavirus. The study site was moved from Waco, TX to Denver, CO, and the IRB documents are still in the

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.

Professional development: This project provided an opportunity for professional development for post-doctoral researchers Dr. Rebekka Dieterich-Hartwell and Dr. Jacelyn Biondo as they conducted the qualitative grounded theory data analysis and, as a result, increased their knowledge in the area of qualitative research and GWI. It also provided an opportunity for professional development for doctoral student Bani Malhotra as she was mentored in the process of developing a MOOC curriculum.

The results from the grounded theory study were presented at the virtual VA-DoD Gulf War Illness State of the Science Conference in August 2020. A post presentation scheduled for the Military Health System Research Symposium in Kissimmee, FL, was canceled due to the Coronavirus pandemic. An abstract was also accepted to an invited session at the annual meeting of the Society for Brain Mapping and Therapeutics in March 2020, but the conference was canceled due to COVID-19 and is rescheduled for March 2021

Future opportunities: It is expected that the findings from this study will continue to be disseminated at conferences and/or workshops related to qualitative research and military health care.

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.

Findings were shared at the VA-DoD Gulf War Illness State of the Science Conference in August 2020. Veterans at the meeting expressed interest in participating in the study.

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.

During the next reporting period we plan to complete data collection and data analysis for Aim 2 (Gulf war Veterans), disseminate the results to communities of interest, present the results at conferences and workshops, and submit for publications. We also plan to complete the curriculum for the MOOC (Aim 3) during this period.

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).

This study is one of the first to examine the lived experiences of Veterans with GWI and their needs as they encounter the aging process. The findings from this study are likely to make an impact on the base of knowledge, theory, and research by advancing patient care through educating health care providers about the unique needs of this population. The educational materials (including patient narratives) are expected to reduce the unique barriers to care faced by this group of Veterans. The MOOC curriculum (Aim 3), once completed, will help identify practices healthcare providers need to adapt to, in order to better serve patient needs.

What was the impact on other disciplines?

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

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.

Both the discipline of military health, military medicine, qualitative research and art therapy as well as other disciplines are likely to be impacted by the findings of this study.

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.*

The third Aim of this study is to create a curriculum for a MOOC (massive online open course) which could possibly be shared with civilian physicians as well.

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.*

The findings from this study are likely to make an impact on society by improving the attitudes towards Gulf War Illness by helping clinicians become more empathic care providers and reducing the barriers to care faced by Veterans with GWI, thus ultimately advancing patient care.

5. **CHANGES/PROBLEMS:** The Project Director/Principal Investigator (PD/PI) is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer 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.

One change we have faced on the project is the move of Dr. Bryann DeBeer (Site PI). Dr. DeBeer transferred to the University of Colorado in February of 2020. This study is now being run out of the University of Colorado, but recruits from the Department of Veterans affairs Eastern Colorado Health Care System. Therefore, a VA IRB is required. In March of 2020, the Department of Veterans affairs shut down all VA research in response to the pandemic. Dr. DeBeer worked with VA Research Service to make all study activities remote. The VA had never done a remote study similar to this before; thus, Dr. DeBeer had to work with the IRB to develop new procedures. At this site, there is a Co-Institutional IRB. The University and the VA do a first layer of review (2 separate committees at VA) to approve study procedures and then it goes on to the co-institutional IRB. Due to having to make changes to the protocol to take it online, once Dr. DeBeer submitted the IRB to the VA for review, several rounds of review were necessary for approval. Currently, the project is under review by the IRB and approval is expected shortly. Thereafter we will submit to HRPO and expect to complete the remaining data collection with veterans in 2021. We have discussed these changes and they have been approved from the funding agency and officers.

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).*

Kaimal, G. & Dieterich-Hartwell, R. (under review). Grappling with Gulf War illness: Perspectives of health care providers. *International Journal of Environmental Research and Public Health*. Please see attachment.

- **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.*

Kaimal, G. & Dieterich-Hartwell, R. *Grappling with Gulf war illness: perspectives of health care providers and veterans*. Virtual VA-DoD Gulf War Illness State of the Science Conference, August 2020.

Kaimal, G. & Dieterich-Hartwell, R. *Grappling with gulf war illness: perspectives of health care providers and veterans*. Military Health System Research Symposium, Kissimmee, FL, August 2020 (conference canceled due to public health emergency)

Pashtun, S., Gray, R., Bodurka, J., Tegeler, C., Kaimal, G., (March 20th 2020). Military medicine panel. Society for Brain Mapping and Therapeutics national conference, Los Angeles, CA.

- *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.*

This study was highlighted under research in the program book on the cdmrp.army.mil website (Congressionally Directed Medical Research Programs):

<https://cdmrp.army.mil/gwirp/pbks/gwirppbk2020.pdf>

- **Technologies or techniques**

Identify technologies or techniques that resulted from the research activities. In addition to a description of the technologies or techniques, describe how they will be 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. State whether an application is provisional or non-provisional and indicate the application number. 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;*
- *biospecimen 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.”

*Name: Girija Kaimal, EdD, ATR-BC
Project role: Principal Investigator
Researcher identifier (Orcid ID): 0000-0002-7316-0473
Nearest month person worked: 1.8*

*Name: Bryann de Beer, PhD
Project role: Site Principal Investigator
Nearest month person worked: 2*

*Name: Rebekka Dieterich-Hartwell, PhD, BC-DMT
Project role: Postdoctoral research fellow
Research identifier (Orcid ID): 0000-0002-9788-7140
Nearest month person worked: 6 months*

*Name: Jacelyn Biondo, PhD, BC-DMT
Project role: Postdoctoral research fellow
Nearest month person worked: 1.5 months*

*Name: Bani Malhotra, MA, ATR
Project role: Research assistant
Nearest month person worked: 1.5 months*

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)

Partner’s contribution to the project (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.*

Nothing to report

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS: For collaborative awards, independent reports are required from BOTH the Initiating 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.

A manuscript under review is included.