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

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# REPORT DOCUMENTATION PAGE

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<b>14. ABSTRACT</b>  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 were 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 included narrative interviews as well as collage self-portraits of Veterans' experiences of living with GWI. This research led to the development of an educational curriculum for healthcare providers that includes recent research on GWI and qualitative perspectives from a range of Veterans living with the illness. The timeline for the study was four years which included a 1 year no cost extension due to the delays caused by COVID. All data collection and analyses is now complete. Three papers have been generated from the study (two published and one under review). Years one, two and three involved data collection in the form of interviews with Veterans and healthcare providers and analyses of these data. The final year focused on the development of the curriculum based on findings from the study. These curriculum materials will be provided and accessible on a website from the PI's university. 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.					
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## 1. INTRODUCTION:

This systematic qualitative research project examined 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 were of particular interest. Furthermore, perceptions and experiences of health care providers of Veterans with GWI were gathered (Aim 2). The final aim (Aim 3) was to develop an up-to-date curriculum that can be presented through a massive open online course. Overall, 40 Veterans and 10 health care providers were interviewed. Collage portraits of experiences with GWI were also collected from Veterans.

## 2. KEYWORDS:

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

## 3. ACCOMPLISHMENTS:

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

The project goal was to conduct the first ever qualitative study of Gulf War Illness with the aim of understanding the lived experience of veterans who served in the 1990-91 Gulf War. Some of them 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 were 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 included narrative

interviews as well as collage self-portraits of Veterans’ experiences of living with GWI. This research led to the development of an educational curriculum for healthcare providers that includes recent research on GWI and qualitative perspectives from a range of Veterans living with the illness. The study was conducted in collaboration with two veterans’ serving sites including in Waco Texas and in Denver Colorado. The timeline for the study was four years which included a 1 year no cost extension due to the delays caused by COVID. All data collection and analyses is now complete, Three papers have been generated from the study (two published and one under review). Years one, two and three involved data collection in the form of interviews with Veterans and healthcare providers and analyses of these data. The final year focused on the development of the curriculum based on findings from the study. These curriculum materials will be provided and accessible on a website from the PI's university, 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.

<b>MONTHS</b>	<b>MAIN PROJECT MILESTONES <u>SPECIFIC AIM 1 &amp; AIM 2</u></b>	<b>ACCOMPLISHED</b>
	<b>Task 1: Hiring, regulatory compliance, and reporting</b>	
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
	<b>Task 2: Recruit and enroll Veterans and begin data collection</b>	
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

<b>MONTHS</b>	<b>MAIN PROJECT MILESTONES</b>	<b>ACCOMPLISHED</b>
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	yes
	First transcript transcribed and entered into database	yes
	<b>Task 3: Continue data collection and data analysis</b>	
6 – 23	Continued data collection for Aim 1 (veteran experiences)	yes
	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	yes
14 – 24	Complete axial and selective coding	yes
18 – 24	Identify themes and grounded theory framework; review findings with research team	yes
	<b><u>SPECIFIC AIM 3</u></b>	
	<b>Task 4: Create MOOC, disseminate findings and prepare final reports</b>	
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	yes
33 – 36	Complete the MOOC course content and curriculum and submit to funder	yes
33 – 36	Submit manuscripts for dissemination and prepare final reports for project	yes, 3 manuscripts submitted, 2 published, one under review

### **1. Major activities:**

The major activities during this reporting period included:

- Completing the content for a MOOC (Aim 3), along with power point presentation and presentation notes. All four units were finalized during this reporting period.
- Completing data collection (both interview responses as well as collage portraits/graphic responses about veteran experiences with GWI) – during this period, 19 more veterans were recruited and participated in this study, resulting in a total of 40 veteran participants overall.
- Completing data analysis of all accumulated data (40 participants in total)
- Submitting a research article to Military Psychology Journal (currently under review)

### **2. Specific objectives**

The specific objectives during this reporting period included (1) completing Task 3: Data analysis: coding scheme, review analysis with two other coders, axial and selective coding, develop grounded theory framework) and (2) completing Task 4: finish all 4 units for MOOC

### **3. Significant results/key outcomes**

MOOC curriculum including 4 slide presentations and accompanying documents

### **4. Other achievements**

Submission of research article “Living with Toxic Wounds: The Voices and Visual Self Representations of Gulf War Veterans” (11/6/22) to the Military Psychology Journal

### **5. Goals not met**

N/a.

Although there were several challenges throughout the four years of this award period (e.g., site change that required a new IRB and new recruitment efforts, the beginning and continuation of the COVID pandemic), all goals that were set were met in the end.

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

**Professional development:** This project provided ongoing opportunities for professional development for doctoral students Bani Malhotra and Asli Arslanbek and post-doctoral researcher Rebekka Dieterich-Hartwell. During this period, they analyzed and coded the interview data and the graphic responses from the veterans and engaged in the mentored process of developing and completing a MOOC.

Moreover, throughout the four-year award period, there were multiple rich opportunities for professional development and learning. The ongoing challenges offered chances to pivot and think outside the box. For example, during a long stretch when no data could be collected, the team found a creative solution by developing and publishing a methods paper about the already existing data, thus not losing momentum. This was an opportunity for all to obtain greater proficiency in resilience and problem solving.

Overall, the one-on-one work with a mentor and the collaboration on the team were invaluable experiences, particularly for Bani Malhotra, Asli Arslanbek, and Dr. Rebekka Dieterich-Hartwell.

**How were the results disseminated to communities of interest?**

The development of the MOOC as well as the PowerPoint presentations and open access articles will all be accessible on the PI's laboratory (HALE - Health Arts Learning and Evaluation) website: <https://drexel.edu/cnhp/research/faculty/KaimalGirija/>

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

This is the final report and so there is nothing to report.

**4. IMPACT:**

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

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 content modules (Aim 3), will help identify practices healthcare providers need to adapt to in order to better serve patient needs.

*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?**

The MOOC (massive online open course) curriculum content modules is relevant to and can be shared with both military and civilian physicians.

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

The findings from this study with the overarching theme of the importance of validation, 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:**

**Changes in approach and reasons for change**

Nothing to report

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

Nothing to report

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

Nothing to report

**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.**

Dieterich-Hartwell, R., Malhotra, B., Arslanbek, A., DeBeer, B., Alverio, T., & Kaimal, G. Living with Toxic Wounds: The Voices and Visual Self-representations of Gulf War Veterans. *Military Psychology* (under review).

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

Nothing to report

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

Nothing to report.

- *List the URL for any Internet site(s) that disseminates the results of the research activities.*

Nothing to report.

- **Technologies or techniques**

Nothing to report

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

Nothing to report

- **Other Products**

The MOOC curriculum content modules (4 PowerPoint presentations with word documents to go along) are going to be available on following website:  
<https://drexel.edu/cnhp/research/faculty/KaimalGirija/>

## **7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS**

**What individuals have worked on the project?**

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

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

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

*Name:* Tabitha Alverio, MA  
*Project role:* Site coordinator  
*Nearest month person worked:* 2 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?**

Nothing to report

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

Nothing to report

Nothing to report

## **8. SPECIAL REPORTING REQUIREMENTS**

**COLLABORATIVE AWARDS:**

**QUAD CHARTS:**

## **9. APPENDICES:**

The MOOC, PowerPoint slides, and accompanying materials are attached. The submitted research article is also attached.