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

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7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)

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13. SUPPLEMENTARY NOTES

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 resource 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 will 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

16. SECURITY CLASSIFICATION OF:			**17. LIMITATION OF ABSTRACT**	**18. NUMBER OF PAGES**	**19a. NAME OF RESPONSIBLE PERSON**
a. REPORT	**b. ABSTRACT**	**c. THIS PAGE**			**19b. TELEPHONE NUMBER** *(include area code)*
Unclassified	Unclassified	Unclassified	Unclassified	26	

Standard Form 298 (Rev. 8-98)

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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 are gathered (Aim 2). The final aim is to prepare an up-to-date curriculum that can be presented through a massive open online course. Over the course of 2 years, 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	ACCOMPLISHED
	SPECIFIC AIM 1 & AIM 2	
	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
	Task 3: Continue data collection and data analysis	
6 – 23	Continued data collection for Aim 1 (veteran experiences)	32% complete (8 veterans interviewed as of 10/10/19)
	Continued data collection for Aim 2 (HCP experiences)	90% complete (8HCPs interviewed as of 10/10/19)
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	no
14 – 24	Complete axial and selective coding	no
18 – 24	Identify themes and grounded theory framework; review findings with research team	no
	SPECIFIC AIM 3 **Task 4: Create MOOC, disseminate findings and prepare final reports**	
24 – 25	Create template for unit readings, course content, etc.	no
24 – 25	Coordinate subject matter experts to create curriculum Units including course content, lectures, Powerpoint Slides, assignments and assessments	no
24 – 30	Create unit with lay summaries, Veterans' perspectives and art work on experiences with GWI	no
25 – 30	Create course content and review for consistency; ensure that the literature is current and includes most recent research on GWI; gather feedback	no
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	no

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 steps towards the first two aims: (1) to conduct a grounded theory study to understand the experiences of Veterans with GWI including differences by demographics like gender, age, race/ethnicity and type of exposure (2) to conduct a grounded theory study to gather the perspectives of healthcare providers serving Veterans with GWI. More specifically, veterans were recruited through existing studies as well as flyers at the Waco, TX site. In total,15 veterans were enrolled in the study, but one was declined as he exceeded the age criteria. Data has therefore been collected from 14 veterans to date. Interview transcripts have been completed, been de-identified and entered for further data analysis for eight veterans. Vetyerans were recruited through existing studies at VISN17 CoE in TX. Eight healthcare providers have been recruited and interviewed to date. The interviews have also been transcribed, de-identified and readied for further data analysis.
2. **Specific objectives**
   The specific objectives during this reporting period included (1) Major Task 1: Hiring, regulatory compliance, and reporting (2) Recruit and enroll Veterans and begin data collection and (3) Continue data collection
3. **Significant results/key outcomes**
   During this reporting period there were no significant results, only developments
4. **Other achievements**
   n/a
5. **Goals not met**
   During this reporting period one of the challenges that occurred was that the study site is in the process of being moved from Waco, TX to Denver, CO, which means that the IRB documents have to be resubmitted. They were initially submitted to the CTVHCS (Central Texas Veterans Health Care System) and will now have to be submitted to the University of Colorado School of medicine (affiliated with MIRECC Denver).

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

Professional development: This project provided an opportunity for professional development for doctoral students Kathryn Snyder and Rebekka Dieterich-Hartwell. They worked one-on-one work with a mentor (Dr. Kaimal) to learn about the process and implementation of the grant awards. In addition, they learned to work on qualitative data collection including transcribing interviews and entering them into the data analysis software Dedoose). This has resulted in increased knowledge in the area of qualitative research and grants management.
Future opportunities: It is expected that the findings from this study will 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.

Nothing to report

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 (1 year), we plan to complete data collection and data analysis for both Aim 1 and Aim 2.

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 will be 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 MOOC (Massive Online Open Course) curriculum, which could possibly be shared with civilian physicians as well. This is especially salient since veterans are now allowed to access 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 of the changes that is affecting this study is the transfer of the study site from Waco, TX to Denver, CO. This transfer implies a new IRB submission (including HRPO review) that is going to happen during the beginning of the next reporting period. The consent forms, protocols, advertisements, and recruitment materials will have to be modified and submitted to the University of Colorado school of Medicine which is connected to the VA. This will cause a stall in data collection for veterans for a few months.

Actual or anticipated problems or delays and actions or plans to resolve them
Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

There may be delays in the resubmission process to the VA ECHCS that are outside of our control. However, these should not interfere with the goals in the next reporting

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).*

Nothing to report

  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.*

Nothing to report

- **Website(s) or other Internet site(s)**
  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.

Nothing to report

- **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."

Example:

Name:	*Mary Smith*
Project Role:	*Graduate Student*
Researcher Identifier (e.g. ORCID ID):	*1234567*
Nearest person month worked:	*5*
Contribution to Project:	*Ms. Smith has performed work in the area of combined error-control and constrained coding.*
Funding Support:	*The Ford Foundation (Complete only if the funding support is provided from other than this award).*

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: Christina Burns, BA
Project role: Research assistant
Nearest month person worked: 12

Name: Rebekka Dieterich-Hartwell, PhD, BC-DMT
Project role: Research assistant
Research identifier (Orcid ID): 0000-0002-9788-7140
Nearest month person worked: 4.8

Name: Kathryn Snyder, MA, ATR-BC
Project role: Research assistant
*Nearest month person worked:*2.4

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.

Dr. Davidson is no longer the PI of the project due to changes in her position at the VISN Center. We may bring her back as a consultant. Dr. Bryann deBeer will be the PI for the subaward in the coming two years.

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 detailed literature review on Gulf War Illness included below:

Healthcare for Veterans with Gulf War Illness – Literature Review

Rebekka Dieterich-Hartwell & Girija Kaimal
Drexel University College of Nursing and Health Professions

Background

Between August of 1990 and February of 1991, the United States and over 30 coalition countries deployed troops to the Persian Gulf under Operation Desert Storm and Operation Desert Shield, a mission launched in opposition to Iraq's invasion of Kuwait. In total, nearly 1 million service members, among them 700,000 troops from the US, served in these short-term yet large-scale efforts. Numerous of them were exposed to biological and chemical agents, such as fumes of oil well fires, pesticides including carbamates and organophosphates, and other toxins (Maule et al., 2018; White et al., 2000). Furthermore, the anticholinergic drug pyridostigmine bromide was routinely administered as prophylaxis against the nerve agent soman (Mawson & Croft, 2019). Within months of their return, many service members began to report multiple symptoms of illness that were difficult to explain. Symptoms included pain, headache, fatigue, respiratory problems, gastrointestinal issues, memory and cognitive defects, and skin abnormalities, as well as mood changes (Iversen, Chalder, & Wessely, 2007).

It took several years before the possibilities of a Gulf War syndrome were considered. A lack of etiological or pathophysiological evidence left the cluster of ill-defined symptoms without legitimacy, resulting in little support or medical benefits from the VA or DoD (Mahoney, 2001; Nettleman, 2015). In a systematic review, Thomas et al. (2006) identified that veterans of the Persian Gulf War reported more symptoms of pain than personnel who were not deployed to that theater, suggesting that the clusters of symptoms represented a syndrome rather than PTSD or other psychosomatic illness. In 2008, a committee formed by Congress and guided by the White House released a report that stated Gulf War illness was a real disease, distinct from stress-related syndromes (Research Advisory Committee on Gulf War Veteran's Illnesses, 2008).

Despite these findings, the challenges of a clear illness definition continued over the next eight years, with a wide variation in symptoms as well as symptoms overlapping with those of other diseases (Maule et al., 2018; White et al., 2016). Many Gulf War veterans felt invalidated and frustrated as a clear etiology and medical recognition was missing (Greenberg et al., 2018). A report by the Government Accountability Office showed that the VA approved only 17% of claims for compensation for veterans with GWI between 2011 and 2015, three times lower than all other claimed disabilities during this time (United States Government Accountability Office, 2017). Furthermore, Gulf War veterans seeking benefits had to wait four months longer on average to hear back from the VA at that point (United States Government Accountability Office 2017). In 2014, after over two decades of ambiguity, the Journal of the American Medical Association announced that the Institute of Medicine (now the National Academy of Medicine) was advocating for researchers and clinicians to use a particular set of criteria to identify Gulf

War veterans with chronic multi-symptom illness (Kuehn, 2014). This advocacy and the associated book outlines Gulf War illness (GWI) as a specific illness that falls under the chronic multi-symptom illness (CMI) umbrella and has two official case definitions, one put forth by investigators for the Centers for Disease Control and Prevention (CDC), the other being the Kansas criteria.

Notwithstanding these efforts for a clearer grasp on GWI, a continued low and inconsistent rate of approvals of claims for Veterans with GWI has most recently resulted in the call for the development of a single case definition of GWI (Department of Defense, 2018). Thus, in 2018 the Department of Veterans Affairs formed a working group to review current literature, progress towards a single case definition, and address short- and long-term actions in regard to GWI (US Department of Veterans Affairs, 2018).

Case Definitions and Symptoms

Today, over 200,000 deployed veterans, approximately 30%, continue to be affected by the chronic symptoms of GWI (Maule et al., 2018). Between 29% and 60% of Gulf War veterans meet the CDC's criteria for GWI, while 34% of veterans meet the Kansas criteria (Kuehn, 2014). As per the more inclusive and general CDC definition, veterans are diagnosed with GWI if they report one or more symptom(s) that last for 6 months or longer in two of three categories: fatigue, musculoskeletal pain (joint pain, joint stiffness, or muscle pain) and mood/cognition (depression, difficulty in remembering, anxiety, difficulty in sleeping, etc.) (Fukuda et al., 1998). According to a recent meta-analysis of self-reported health symptoms in Gulf War veterans, the most commonly reported symptoms were fatigue, pain, cognitive and mood problems, skin rash, gastrointestinal issues, and respiratory concerns (Maule et al., 2018). This symptom complex lined up with the more specific Kansas definition which identifies GWI in those who report moderate levels of symptoms in three of six categories in the year before the assessment: fatigue/sleep, pain, neurological/cognitive/mood, respiratory, gastrointestinal, and skin (Steele, 2000). A third more restrictive definition, put forth by Haley, includes three symptom complexes: Syndrome 1 (compromised cognition) entails problems with attention, memory, sleep, and depression; syndrome 2 (confusion/ataxia) is characterized by thinking and balance symptoms; and syndrome 3 (neuropathic pain) requires self-reported joint and muscle pain (Haley, Kurt, & Hom, 1997). While the CDC and Kansas definitions are officially recognized, the Haley syndromes are not accepted by the Institute of Medicine.

Longitudinal studies on GW veterans suggest that GWI may "be getting worse over time" (Janulewicz et al., 2017, p.2), particularly with respect to cognitive symptoms (Marlowe, 2001). Furthermore, it remains unclear which functional brain areas are impaired most (Janulewicz et al., 2017) and how this impairment affects the veterans psychosocially today. Veterans with GWI might face faster declines in functioning compared to peers without GWI (Cooper et al, 2016; Hubbard et al 2014; Janulewicz et al, 2017) and present with greater disability than other Veterans of the same era that were not deployed to the Persian Gulf. In animal studies mimicking conditions similar to GWI there is evidence of long-term impacts on depressive behavior, lack of motivation, and memory defects (Parihar et al., 2013; Zakirova et al., 2015). Further, these functional deficits are associated with hippocampal pathology typified by decreased neurogenesis, partial loss of neurons (Parihar et al., 2013) and a persistently elevated oxidative stress and inflammation (Emmerich et al., 2017) akin to the symptoms of an early onset of aging. Given the animal models, the effect that aging will have on this unique, vulnerable population remains a matter of significant concern.

Higher rates of miscarriages and birth defects among Veterans with GWI have been reported (Kang & Bullman, 2001), as have higher rates of accidental deaths compared to rates of death due to disease, especially for female GW Veterans (Kang & Bullman, 2001). The prevalence of GWI also varies, with the highest rates being among those who were in Iraq and/or Kuwait (42%) and among those who departed in June or July of 1991 (41%) (Steele, 2000). In addition, 7% of Veterans from the GW were women, and there have been no studies that examine qualitative differences in experiences by gender. Such studies are needed, especially because many of these women will be transitioning to menopause and post-menopause (Coughlin, 2016).

Causes of Gulf War Illness

Given varying locations of deployment and different countries of units with subsequent varying exposures, no single cause of GWI exists; instead a number of factors are believed to play a role in the pathogenesis of GWI (Kerr, 2015; Kilshaw, 2008; Nettleman, 2015). For example, the heavy use of pesticides intended to prevent arthropod born infectious diseases resulted in overexposure to 15 potentially toxic substances of approximately 40,000 US service members, including organophosphates, carbanates, pyrethroids, and highly concentrated DEET (Research Advisory Committee on Gulf War Veteran's Illnesses, 2008). Prophylactic pyridostigmine bromide (PB) pills were distributed to US, UK, and Canadian troops against possible exposure to the nerve agent soman during an attack by enemy troops (Golomb, 1999). These PB pills, distributed to ca. 400,000 US military personnel, have been found to inactivate important enzymes and cause altered gene expression and delayed cognitive symptoms (Kerr, 2015). Service members were also exposed to dioxins and furans in smoke from over 65 oil well fires. Heightened dioxin levels can lead to skin rashes, fatigue, headaches, or insomnia (Schecter, Birnbaum, Ryan, & Constable, 2006). About 250,000 US soldiers were exposed to chemical warfare agents, such as sarin and sulfur mustard, which can cause eye, skin and respiratory damage as well as a range of systemic effects (Kerr, 2015). According to a recent study, there is a significant association between pesticide exposures and GWI (DeBeer et al., 2017). Smoke inhalation on the other hand was not correlated was not associated with GWI symptoms.

Treatment

Gulf War illness is a complex, chronic, and multilayered illness with a wide variation in symptoms. To this date, no standard level of care exists (Conboy et al., 2016, Department of Defense, 2018; Gulf War Illness Research Program, 2016; Minshall, 2014; White et al., 2016). Most frequently it is treated similar as other chronic multisymptom illnesses, such as Fibromyalgia, Chronic Fatigue Syndrome, and Functional gastrointestinal disorders (US Department of Veterans Affairs, 2018).

According to the VA/DoD clinical practice guidelines for the management of chronic multisymptom illness (Department of Veterans Affairs/Department of Defense, 2014), cognitive behavioral therapy is the recommended treatment for GWI that manifests with no predominant set of symptoms. A recent report of Gulf War veteran's experiences showed that most treatments pursued were for pain (Baldin et al., 2019). For GWI with mostly pain symptomatology, acupuncture has been a treatment of choice as it is safe, widely available, and cost-effective (Burk et al., 2006; Hall et al., 2012). In a randomized clinical trial study, 82 veterans diagnosed with symptoms of GWI received six months of biweekly acupuncture

treatments (Group 1) or two months of waitlist with subsequent weekly acupuncture treatments (Group 2) (Conboy et al., 2016). The authors found that participants in Group 1 had both a clinically and statistically significant average improvement of pain compared to Group 2. Regarding GWI with fatigue predominance, a trial of antidepressants (either serotonin-norepinephrine reuptake inhibitor or tricyclic antidepressants) has been recommended (Department of Veterans Affairs/Department of Defense, 2014). Furthermore, Kaiser (2016) suggested a combination of a low-dose stimulant drug and a nutrient formula intended to support mitochondrial health specifically for GWI with predominant chronic fatigue, decreased alertness, poor concentration and cognitive decline.

Experience of Gulf War Illness

Given its complex nature of clustered, varying and long-term symptoms, GWI has been investigated from a variety of viewpoints as well as case definitions (Smith et al., 2013). However, despite the passage of over 2 decades since the Gulf War, there have been no US studies to date that focus on the individual and unique experiences of Veterans with GWI, including their perceptions of the impact of their illness, quality of care, barriers faced, and related impact on interpersonal relationships and quality of life. It is also unclear what effect aging has on this population and what role demographics like gender, race, ethnicity, and context of exposure play. Lack of recognition of the illness, redirected resources, and misperceptions of the nature of GWI have led to a concern that some veterans do not trust the VA to serve them effectively due to perceived skepticism about the validity of their illness (Gulf War: What kind of care are veterans receiving 20 years later, 2013). A recent quality improvement survey confirmed this notion. While a majority of the 30 GWI veterans who participated reported that their VA HCPs were supportive, some said they felt their HCPs did not believe them or trust their reported symptoms, ascribed their symptoms to mental health issues, denied that GWI existed, or did not have the information necessary to help (Baldwin et al., 2019, p. 214). Participants furthermore suggested improvements to GWI care such as available research updates and updated education for HCPs (Baldwin et al., 2019).

Early accounts of GWI in UK veterans, collected in 1996 and 1997, highlighted a notion of fear and a loss of trust and safety in both the body and the military structure (Cohn, Dyson, & Wessely, 2008). A qualitative study from 2008 focused on psychiatry, the military, and the experience of GWI specific to the United Kingdom (Kilshaw, 2008). Through in-depth semi structured interviews Kilshaw (2008) learned that the Gulf veterans largely viewed their psychiatric symptoms as chemically induced and were dismissive of psychiatric explanations pointing towards the stigma of psychiatric labelling. While efforts have been made to explore clinical treatments for GWI (Conboy et al., 2016; DeBeer et al., 2017), there remains a critical need to understand the current experiences of American veterans with GWI, including foregrounding patient voices and understanding their needs and concerns regarding quality of life and quality of care received. Qualitative studies enrich scientific knowledge beyond what can be gained in aggregated and large-scale quantitative studies (Verhoef et al., 2005) by collecting and analyzing data on the similarities and differences between participants' subjective individual lived experiences (Creswell, 2009; Lincoln & Guba, 1994; Paterson & Britten, 2004). Although large-scale quantitative studies provide valuable information about overall trends based on specific questions, they do not provide information about individual decision-making processes or about experiences that enable or serve as barriers to effective health care. Individual, richly nuanced life story narratives could help health care providers better understand the human scale

of the barriers and challenges faced by veterans with GWI and what they seek in their care. In addition to narratives and life stories, visual images are also impactful in ensuring retention of information (Hollands & Marteau, 2013) and evoking empathy in the viewer (Genevsky, Ashfall, Solvi, & Knutson, 2013; Potash, Ho, Chick, & Yeung, 2013). Qualitative narrative and visual data can thus personalize and humanize patient experiences and sensitize health care providers to provide effective, empathic, and improved care for this chronic, complex health condition (Dursa et al., 2016).

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