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Efficacy of Treatments Tried: A Survey of Gulf War Veterans

Principal Investigator: GOLOMB, BEATRICE

Institution Receiving Award: CALIFORNIA, UNIVERSITY OF, SAN DIEGO

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PUBLIC ABSTRACT

Background: It has been 20 years since the Persian Gulf War, following which an estimated one-quarter of servicepersons developed chronic multisystem health problems. Gulf War veterans (GWV) have long urged that information be procured about effective treatments for Gulf War illness (GWI). There may be effective treatments that GWV have tried. There may be harmful and costly treatments that GWV are currently trying -- in the absence of dissemination of others' experiences, by which they might know better.

Increasing evidence supports the utility of asking patients about their treatment experience to learn about treatment effects. Patient reports have been found to be reliable, and patients' attributions of what was due to the treatment have been found to be largely valid. Such factors underlie the European Union's plans to uniformly implement patient-targeted "pharmacovigilance" looking for adverse effects of treatment by asking patients. It has been noted that listening to patients earlier would have accelerated identification of key adverse effects of treatments. To date, no effort has been made to systematically harvest the treatment experiences of ill GWV in order to learn from them.

Goal: We propose to conduct a national survey study asking GWV to share their treatment experiences.

Methods: Our goal will be to collect treatment information from at least 500 GWV. First, we will learn about the veterans -- their age, sex, health conditions, habits, and Gulf-related exposures, and their symptoms, in case these prove to be important in what treatments help or hurt. We will ascertain who formally meets criteria for GWI and who is affected by symptoms compatible with GWI, but with coexisting medical conditions that may exclude them from GWI treatment trials. Next, we will ask them to list all treatments they have tried. This will give a sense of the spectrum of treatments that have been tried, providing perspective on which, and how many, treatments GWV with GWI are trying. Third, we will ask them which were the most recent and which had the greatest impact -- good or bad. In case they are unable to take time to give detailed information about each and every treatment tried over 20 years and how it affected them, our hope is to prioritize information on those for which recall will be strongest (recent treatments) and/or impact greatest. For the treatments that were most recent, and those perceived as most favorable -- and most adverse -- we will ask detailed information about the character of the treatment (type, brand, dose, frequency, duration, and other details as relevant); the apparent short-term effects (and which symptoms were affected); and the apparent long-term effects. For effects both favorable and adverse: Did effects persist, dissipate, or reverse with time after treatment, or with continued treatment? Were there significant costs or complications? Were there major benefits, or harms -- in the short term, and final analysis -- to quality of life?

Analysis: We will provide descriptive analyses, of which treatments veterans with GWI have tried; how many; and with what success or harm. We will characterize which treatments have been perceived, by those reporting, as most consistently favorable or adverse --

overall, and for each of a set of key symptoms important in GWI. For treatments that vary markedly in their reported impact, we will see if we can identify factors, "effect modifiers," that determine how, or in whom, the treatment has been perceived as beneficial (or adverse).

Impact: This study serves important functions. First, it will provide a vision of which treatments, and how many, reporting which GWW have appealed to, to seek relief for their suffering. Second, it will provide information about which treatments present the most promising avenues of future study, which may accelerate development of effective treatments. Third, it will provide information about which treatments have been most consistently unhelpful or harmful, or futile but costly, so that veterans and their providers can, if they choose, avoid the risks attending such treatments. Finally, inspection of patterns of treatments that cause benefit or harm may lead to new insights into mechanisms of GWI. The resulting advances in understanding of GWI may in turn lead to studies of mechanism, and development of still more effective treatments, to help those for whom GWI is a lasting legacy of their service to their nation.

Thus, this study may provide benefits now, from avoiding consistently harmful treatment approaches, intermediate benefits from accelerated study of the most promising candidate treatments, and long-term benefits from insights into mechanisms that may foster development of new, still more effective treatments.

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