**Veterans with Gulf War Illness perceptions of management strategies**

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**Abstract**

*Aims:* Gulf War Illness (GWI) is a prevalent and disabling condition characterized by persistent physical symptoms. Clinical practice guidelines recommend self-management to reduce the disability from GWI. This study evaluated which GWI self-management strategies patients currently utilize and view as most effective and ineffective.

*Materials and Methods:* Data were collected from 267 Veterans during the baseline assessment of a randomized clinical trial for GWI. Respondentsanswered 3 open-ended questions regarding which self-management strategies they use, view as effective, and view as ineffective. Response themes were coded, and code frequencies were analyzed.

*Key findings:* Response frequencies varied across questions(in-use: *n*=578; effective: *n*=470; ineffective: *n*=297). Healthcare use was most commonly used management strategy (38.6% of 578), followed by lifestyle changes (28.5% of 578), positive coping (13% of 578), and avoidance (13.7% of 578). When asked about effective strategies, healthcare use (25.9% of 470), lifestyle change (35.7% of 470), and positive coping (17.4% of 470) were identified. Avoidance was frequently identified as ineffective (20.2% of 297 codes), as was invalidating experiences (14.1% of 297) and negative coping (10.4% of 297).

*Significance:* Patients with GWI use a variety of self-management strategies, many of which are consistent with clinical practice guidelines for treating GWI, including lifestyle change and non-pharmacological strategies. This suggests opportunities for providers to encourage effective self-management approaches that patients want to use.

*Keywords:*Gulf War Illness,medically unexplained symptoms, primary care, self-management, Veteran’s health

**Introduction**

At least 30% of Veterans who deployed to the Gulf War experience chronic and poorly understood physical symptoms across multiple systems including pain, fatigue and gastrointestinal distress [1]. Termed Gulf War Illness (GWI), Veterans with GWI experience significant disability and poor physical functioning [2,3].

 Healthcare for Veterans with GWI is not adequate. Consistent with experiences of civilians with medically unexplained conditions [4], Veterans with GWI report providers dismiss their condition and do not provide treatment recommendations [3]. Providers, in turn, may lack clinical knowledge about GWI and treatment options [5]. As a result of this uncertainty, common across unexplained conditions [6], physicians may rely on pharmacological treatment, inaccurately assuming patients prefer medication [7]. Providers may also seek an etiology to guide treatment by employing excessive assessments, surgeries, and specialty consultations [8-10]. If an etiology cannot be identified, providers may discount patient experiences or stop medical intervention [3,4,11].

Clinical practice guidelines recommend limiting unnecessary assessments and focusing on self-management [12]. However, self-management is not always integrated into treatment [13], possibly because of limited research examining patient self-management preferences. Providers may also be more inclined to treat unexplained and severe symptoms pharmacologically [14], which may reflect perceptions that GWI is difficult to treat with self-management. Greater understanding of self-management preferences among patients with GWI may counteract this bias.

Derived from the literature on chronic illness, chronic symptom self-management strategies [15] include: lifestyle changes (e.g., rest), complementary care (e.g., psychological care) and emotional coping (e.g., symptom acceptance). Self-management also includes uptake of treatment recommendations including pharmacological and non-pharmacological/behavioral treatments (e.g., cognitive behavioral therapy). This is because while providers prescribe medical interventions, patients can and do make the decision to implement treatment recommendations, with as many as 40% of patients not adhering to intervention recommendations [16].

An initial qualitative study with 30 Veterans with GWI found they use several self-management strategies, including taking prescribed medications, lifestyle changes, alternative treatments, and avoidant strategies like pushing through/ignoring symptoms [17]. Civilians with unexplained conditions also use a wide variety of self-management approaches, including primary/complementary care and emotional coping [18,19], with some strategies being valued more than others. Specifically, some patients may grow to view self-management via medical intervention as ineffective, instead relying on lifestyle coping (e.g., behavioral engagement) [19].

 Patients with chronic pain, a condition with substantial overlap with unexplained conditions [20], employ similar self-management strategies. A large quantitative study found patients with chronic pain use four categories of self-management including: passive lifestyle (e.g., rest), active lifestyle (e.g., exercise), cognitive coping (e.g., stress-reduction), and traditional/alternative medical interventions (e.g., taking medications) [21]. Further, patients have preferred self-management strategies, particularly resting, using topical agents (e.g., ice/heat) and taking medications [22-24]. However, it is unknown how self-management preferences among patients with chronic pain and unexplained conditions apply to those with GWI.

This study sought to better understand self-management strategies used by patients with GWI, and which they view as most effective and ineffective. This information is critical to help providers improve care of GWI.

**Materials and Methods**

Data were collected as part of the baseline assessment of a randomized clinical trial comparing Problem-Solving Therapy to Health Education for Gulf War Illness [25]. Institutional Review Board approval and participant informed consent were obtained.

*Participants*

 This sample included 267 Gulf War Veterans. To participate, individuals had to have been deployed to Operations Desert Storm or Shield; have GWI defined by the Kansas definition (i.e., symptoms belonging to three of the six GWI domains including fatigue, pain, neurological/cognitive/mood, skin, gastrointestinal, and respiratory) [1]; and experience disability that was at least half a standard deviation above the mean, or average level of disability within the general population, on the World Health Organization Disability Schedule II [26]. Those who were above the mean by a substantial amount, within our sample, were conceptualized as experiencing more severe manifestations of GWI.

 Exclusion criteria included: current suicidal or homicidal intent, psychosis, and/or a diagnosis of a degenerative brain disorder or psychiatric/medical illness which would impede generalizability, safety, or obscure symptom clarity.

*Measures*

 Within the baseline assessment questionnaire, participants responded to three internally generated, open-ended questions about their GWI management. The questions were, “how do you currently manage your Gulf War Illness,” “what strategies are helpful in managing your Gulf War Illness,” and “what strategies are not helpful in managing your Gulf War Illness?” No limitations were placed on responses, nor did responses have to be mutually-exclusive. Participant responses were evaluated to identify self-management strategies, which were developed into response codes.

*Coding procedures*

 Response coding took place in three steps. First, three authors (NJS, SRT, LMM) developed an initial set of 20 codes after reviewing responses to all three questions. Two authors (NJS, SRT) then examined the first 25 responses to each question to establish interrater reliability and develop needed additional codes (total of ten). Codes were largely identical across questions, with the ineffective strategies question possessing some additional unique codes. Interrater agreement was initially 80%, and 100% after discussion. Using this final set of codes, the same two authors coded the remaining responses. Coders discussed discrepancies until reaching 100% agreement. Responses were assigned multiple codes when applicable, with 100% agreement met only once all authors agreed on the single or set of codes assigned to a given response.

 After codes were tallied, four authors (NJS, SRT, DMW, LMM) consolidated codes. Eight codes were removed due to lack of applicability (e.g., responding to effective strategies by describing ineffective strategies). Additionally, six overlapping codes were collapsed into three codes. The three authors then agreed upon five overarching categories encapsulating the 22-remaining codes for current and effective self-management strategies, and five overarching categories for the 23-remaining ineffective self-management strategies (see supplementary Table 1 for response examples). Frequencies were examined to determine which self-management strategies participants were using, and which they viewed as effective and ineffective.

**Results**

Age ranged from 42 to 79 (*M*=52.9, *SD*=7.3). Participants were mostly male (88%), employed full-time (56%), and identified as White (71%). Participants also identified as Black or African American (22%), American Indian/Alaska Native (5%), Hispanic or Latino/Latina (5%), Asian (1%), Native Hawaiian (<1%), as more than one race (3%), and unknown (<1%).

 *Current strategies*

 Participants first reported which GWI self-management strategies they use (see Table 1). There were 578 coded responses across 259 participants with an average of 2.23 per participant. Eight responses were not coded due to being blank, inapplicable/non-strategies, or unintelligible.

Five overarching categories emerged: (1) healthcare use (2) lifestyle change (3) avoidance (4) positive coping (5) nothing/not knowing. Participants most commonly reported healthcare use strategies (*n*=223 responses, 38.6% of 578 total responses; 57.9% of 259 participants). Medication use was the most frequently reported strategy within the healthcare use category (*n*=107), and also the strategy most frequently reported as in-use across categories. Within the health care use category, other commonly employed self-management strategies included counseling (*n*=50), other medical healthcare options (e.g., “going to the hospital”; *n*=36), and complementary/integrative healthcare (*n=*18).

Veterans also reported commonly using lifestyle changes to self-manage GWI (*n*=165 responses, 28.5% of 578 total responses; 38.6% of 259 participants). Within this category, participants most frequently reported using exercise/activity increase (*n*=54), socializing/relationships (*n*=33), good diet/eating practices (*n*=29), and hobbies/vocations (*n*=23).

 Less often reported categories included avoidance (*n*=79 responses, 13.7% of 578 total responses; 28.6% of participants), and positive coping (*n*=75 responses, 13.0% of 578 total responses; 27.0% of 259 participants). Strategies that fell within these categories included avoidance strategies of pushing through/ignoring symptoms (n=41) and avoiding activity/exercise (n=23), and positive coping strategies such as positive attitude/emotions (n=34) and relaxation/stress reduction (n=27).

Of note, 14.3% of participants reported not knowing of, or not using, self-management strategies for their GWI (*n*=37 responses, 6.4% of 578 total responses).

*Effective strategies*

Participants next reported which GWI self-management strategies they view as most effective (see Table 1). There were 470 coded responses across 251 participants with an average of 1.87 per participant. Sixteen responses were not coded due to being blank, inapplicable/non-strategies, or unintelligible.

 The same five overarching categories emerged. Lifestyle change strategies were most commonly reported as effective (*n*=168 responses, 35.7% of 470 total responses; 45.8% of 251 participants). Strategies within this category that were frequently reported as effective included socializing/relationships (*n*=43), exercise/activity increase (*n*=40) and good diet/eating practices (*n*=23).

Also identified as effective was healthcare use (*n*=117 responses, 25.9% of 470 total responses; 37.5% of 251 participants). The healthcare use strategies most often reported as effective included: taking medication (*n*=43), other medical healthcare options (*n*=31), and counseling (*n*=27). Responses communicating the effectiveness of positive coping were also common (*n*=82 responses, 17.4% of 470 total responses; 29.9% of 251 participants), including relaxation/stress reduction (*n*=36), positive attitude/emotions (*n*=26) and other cognitive self-management tools (*n*=20). Few participants reported avoidance strategies as effective (*n*=51 responses, 10.9% of 470 total responses; 17.9% of 251 participants).

Of note, 20.7% of participants reported not knowing of, or not using, an effective strategy to self-manage GWI (n=52 responses, 11.1% of 470 total responses).

*Ineffective strategies*

Finally, participants reported what strategies they view as ineffective to self-manage GWI (see Table 1). There were 297 coded responses across 226 participants with an average of 1.31 per participant. Forty-one responses were not coded due to being blank, inapplicable/non-strategies, or unintelligible.

Six overarching categories emerged: (1) healthcare use (2) lifestyle change (3) avoidance (4) negative coping (5) invalidating experiences (6) nothing/not knowing/not utilizing self-management strategy. Consistent with avoidance being least often identified as effective, participants most commonly felt these strategies were ineffective (*n*=60 responses, 20.2% of 297 total responses; 24.8% of 226 participants). Strategies most often identified as ineffective within this avoidance category were pushing through/ignoring symptoms (*n*=19) and avoiding activity/exercise (*n*=17).

Participants also reported that healthcare use (*n*=56 responses, 18.9% of 297 total responses; 20.8% of 226 participants) was commonly ineffective, with taking medication most consistently endorsed as ineffective within the healthcare use category (n=40). Lifestyle change (*n*=49 responses, 16.5% of 297 total responses; 17.7% of 226 participants) was also reported as ineffective with the strategy of socializing/relationships (*n*=16) being the lifestyle change strategy most commonly reported as ineffective.

Two new categories emerged from responses about ineffective self-management strategies. Many reported negative coping (*n=*31 responses, 10.4% of 297 total responses; 13.7% of 226 participants), which included negative attitude (*n*=19) and stress (*n*=12). Veterans also described a new category of invaliding experiences (*n=*42 responses, 14.1% of 297 total responses; 17.3% of 226 participants). Veterans described invalidating experiences, or encounters which dismissed Veteran’s experiences with GWI as not true, as negatively impacting GWI self-management. These were not self-management strategies, but indicated contextual factors that made it difficult for participants to self-manage their GWI (e.g., bad healthcare experiences, other people's invalidations).

Finally, 26.1% of participants reported not knowing of, or not using, an ineffective strategy for managing their GWI symptoms (*n*=50 responses, 19.8% of 297 total responses), which included not using specific self-management strategies (e.g., not taking medication; *n*=9).

Table 1

*Frequency of Self-Management Strategies Currently in Use, Viewed as Effective and Ineffective by Veterans with Gulf War Illness (2015-2020)*

|  |  |  |  |
| --- | --- | --- | --- |
| Overarching categories  | Currently in Use(*n=*578 identified strategies) | Effective(*n=*470 identified strategies) | Ineffective(*n=*297 identified strategies) |
| and identified strategies | *n* | *%* | *n* | *%* | *n* | *%* |
| Healthcare use | 223 | 38.6% | 117 | 25.9% | 56 | 18.9% |
| Taking medication | 107 |  | 43 |  | 40 |  |
| Counseling | 50 |  | 27 |  | 8 |  |
| Other medical healthcare options | 36 |  | 31 |  | 4 |  |
| Complementary/integrative healthcare | 18 |  | 10 |  | 1 |  |
| Physical medicine/rehab | 12 |  | 6 |  | 3 |  |
| Lifestyle change | 165 | 28.5% | 168 | 35.7% | 49 | 16.5% |
| Exercise/activity increase | 54 |  | 40 |  | 8 |  |
| Socializing/relationships | 33 |  | 43 |  | 16 |  |
| Diet/eating practices | 29 |  | 23 |  | 7 |  |
| Hobbies/vocations | 23 |  | 21 |  | 10 |  |
| Spirituality | 14 |  | 15 |  | 1 |  |
| Sleep practices | 6 |  | 9 |  | 8 |  |
| Get info on GWI/education | 3 |  | 15 |  | 6 |  |
| Sobriety | 3 |  | 2 |  | 1 |  |
| Avoidance | 79 | 13.7% | 51 | 10.9% | 60 | 20.2% |
| Pushing through/ignoring symptoms | 41 |  | 17 |  | 19 |  |
| Avoiding activity/exercise | 23 |  | 23 |  | 17 |  |
| Isolation | 12 |  | 10 |  | 11 |  |
| Substance use  | 3 |  | 1 |  | 13 |  |
|  |  |  |  |  |  |  |
| Positive Coping  | 82 | 13% | 75 | 17.4% | N/A | N/A |
| Positive attitude/emotion | 34 |  | 26 |  | N/A |  |
| Relaxation/stress reduction | 27 |  | 36 |  | N/A |  |
| Other cognitive self-management tools | 14 |  | 20 |  | N/A |  |
| Negative Coping  | N/A | N/A | N/A | N/A | 31 | 10.4% |
| Negative attitude | N/A |  | N/A |  | 19 |  |
| Stress | N/A |  | N/A |  | 12 |  |
| Invalidating experiences | N/A | N/A | N/A | N/A | 42 | 14.1% |
| Bad healthcare experiences | N/A |  | N/A |  | 22 |  |
| Other people's invalidations | N/A |  | N/A |  | 16 |  |
| Bad life/military experiences | N/A |  | N/A |  | 4 |  |
| Nothing/not knowing | 37 | 6.4% | 52 | 11.1% | 59 | 19.8% |
| Nothing | 23 |  | 26 |  | 19 |  |
| I don't know/I don't know if I have GWI | 14 |  | 26 |  | 31 |
| Not utilizing specific self-management strategies | N/A |  | N/A |  | 9 |

Notes: 259 responses were collected for which strategies participants were currently using, 251 for which strategies participants viewed as effective, and 226 for which strategies participants viewed as ineffective; taking medication conceptualized as an active strategy engaged in to manage symptoms; substance use conceptualized as a tool of avoiding/suppressing one’s problems/symptoms; participants may have asserted employing strategies for some symptoms and also stated employing nothing/not knowing what they are using to self-manage other symptoms; the response code of “I don’t know if I have GWI” likely occurred because, while participants had to possess diagnosable GWI to participate, they did not need to believe they had GWI; N/A refers to a category or code that was not found within responses to one of the questions.

**Discussion**

This study evaluated how patients with GWI self-manage their conditions, and what they view as effective and ineffective self-management strategies. We found that Veterans with GWI use a variety of self-management strategies and had preferences for which were most effective and ineffective.

Strategies consistently communicated as in-use were not always as consistently stated to be effective. The most frequently used strategies were within the healthcare use category, specifically taking medication. While frequently used, taking medication was viewed as both effective and ineffective by similar proportions of participants. Nonpharmacological healthcare (e.g., counseling) was less frequently used, but considered effective by a larger proportion of participants. Lifestyle change, the second most commonly used self-management category, was also most frequently reported as effective and, as compared to the healthcare use category, less often viewed as ineffective. Positive coping was also frequently reported as effective, but fewer participants reported using these strategies compared to healthcare use and lifestyle change. In terms of ineffective strategies, participants identified avoidance and negative coping along with contextual factors that made self-management difficult (i.e., invalidating experiences).

Research suggests that many medical providers believe patients want to treat unexplained conditions pharmacologically [7,14]. However, there is a growing body of literature that indicates this perception is inaccurate [27,28]. Our results support the latter. While patients with GWI reported commonly taking medication, likely prescribed by providers, similar proportions of participants reported taking medication as effective and ineffective for GWI self-management. Further, despite non-pharmacological techniques (e.g., counseling) being less frequently utilized, higher proportions of participants employing these strategies viewed them as effective (e.g., counseling: 54%; complementary/integrative healthcare: 55.56%) when compared to taking medication (40.19%). Similarly, we found that participants consistently identified non-healthcare based GWI self-management strategies as effective. The preference among this sample toward lifestyle change and positive coping supports the limited existing literature identifying non-healthcare-based techniques as valuable and effective management strategies for both unexplained conditions broadly [29] and GWI specifically [30].

However, several valued GWI self-management strategies were underused (e.g., socializing/relationships, relaxation/stress reduction). For example, while 35.7% of responses felt lifestyle coping strategies are effective, only 28.5% of responses reported currently using these strategies. These lower levels of use may be the result of providers not recommending these options [31] or patients not following up on referrals/recommendations [16]. Alternatively, providers and patients may lack access to or awareness of these self-management strategies [32]. Lacking awareness is supported by our results indicating a fifth of the current sample did not know of effective or ineffective self-management strategies for GWI.

In contrast, avoidance strategies (e.g., avoiding activity/exercise) were being used despite being frequently identified as ineffective. These findings are worrisome because avoidant strategies are associated with negative outcomes for unexplained conditions (e.g., increased symptom severity/disability) [33]. Similarly, participants identified contextual factors that hindered self-management including invalidation. As Veterans with GWI often experience invalidation [3], these results suggest that Veterans with GWI may need support to address these to improve their ability to manage GWI.

*Strengths and limitations*

A strength of this study was its use of open-ended survey questions which allowed for the assessment of understudied patient-generated GWI self-management strategies. However, given the sample consisted of Veterans who were primarily white and male, with a restricted age range, and who receive care in the context of the VA, results may not generalize to the wider Veteran population. Additionally, the written format and study design prevented the opportunity for clarification or follow-up questions, limiting data richness. Finally, while data suggests that several effective self-management strategies are underutilized, we did not evaluate barriers or facilitators to using these strategies, such as negative past experiences with a self-management strategy or barriers to implementing a strategy. This should be examined in future studies.

*Implications*

These results have implications for GWI treatment. Provider symptom management recommendations for unexplained conditions are often unclear and vague [34] despite Veterans with GWI valuing provider recommendations [35]. Our results suggest that providers should recommend non-pharmacological treatments (e.g., counseling) and self-management strategies (e.g., exercise/activity increase, relaxation/stress reduction). Veterans not only viewed these strategies as effective, but they are also recommended for GWI treatment [12]. Patients reported a wide-variety of these strategies as helpful, suggesting that providers may want to provide a menu of strategies and use trial and error to tailor interventions for a specific patient. Providers should also consider addressing ineffective self-management strategies with patients to facilitate decreased use of these strategies. Similar to effective strategies, strategies that were deemed ineffective (e.g., ignoring symptoms) are generally viewed as ineffective by the medical community [36]. Importantly, in addition to many Veterans employing ineffective strategies, over 20% of the sample did not know effective or ineffective self-management strategies for GWI. This further supports that providers discussing self-management with Veterans may be key to improving GWI care.

**Conclusions**

In sum, this study suggests Veterans with GWI use a variety of self-management approaches to manage GWI. Further, Veterans with GWI generally find self-management approaches that are recommended by the medical community as effective including, non-pharmacological treatments, lifestyle changes and positive coping. Likewise, self-management approaches not recommended by the medical community (e.g., avoidance) were viewed as ineffective among Veterans. The findings of this study may be helpful to providers in developing comprehensive and tailored management approaches for patients with GWI.

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*Conflict of Interest statement*

The authors declare that there are no conflicts of interest.

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