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Evaluation of secondary post-traumatic stress disorder symptoms in the spouses of chemical warfare victims 20 years after the Iran–Iraq war

Khodabakhsh Ahmadi,¹ Mahmood Reshadatjoo,² GholamReza Karami,¹ Nariman Sepehrevand,² Pegah Ahmadi,² Shahrzad Bazargan-Hejazi³

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¹Baqiatallah University of Medical Sciences, Tehran, Iran; ²Urmia University of Medical Sciences, Urmia, Iran; ³Charles Drew University of Medicine and Science and University of California, Los Angeles, USA

Correspondence to Khodabakhsh Ahmadi (k.ahmadi@bmsu.ac.ir)

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Aims and method Post-traumatic stress disorder (PTSD) has been reported in 90% of chemical warfare victims in previous studies. An individual's traumatic experience(s) may affect the lives of other family members as well. This cross-sectional case–control study compared the prevalence of PTSD symptoms in the husbands, the secondary PTSD symptoms in the wives and also aimed to identify if there was an association between the PTSD symptoms of the couples in the case group. Cases were 150 husband–wife couples where husbands were civilians exposed to chemical warfare; the controls were 156 husband–wife couples where there was no such exposure. Both cases and controls were recruited from Sardasht in Iran; this Kurdish city was attacked by four 250 kg sulphur mustard warheads in June 1987.

Results Across three sets of cut-off points for the Mississippi Scale for Combat-Related PTSD symptomatology (<120 and ≥121; <106 and ≥107; and <65, 65–130 and >130) wives in the case group demonstrated higher rates of PTSD symptoms than did those in the control group; the difference was statistically significant. Furthermore, husbands in the case group had a significantly higher overall mean score (123.0 (s.d. = 17.2)) than the husbands in the control group (112.3 (s.d. = 21.7); $P < 0.001$, $t = 4.80$). There was no statistically significant association between the overall PTSD score of the husbands in the case group with that of their wives ($P = 0.274$, correlation coefficient 0.092).

Clinical implications Husbands who were exposed to the chemical agents reported higher PTSD symptoms and there were higher rates of PTSD symptoms among the wives of individuals who were exposed to chemical warfare. Study results suggest the need for coordinated treatments, policy efforts and interventions to improve the well-being of chemical warfare victims and their caregiver wives.

Declaration of interest None.

Sulphur mustard gas is a chemical warfare agent that was widely used during the First and Second World Wars, and more recently by the Iraqi forces during the 8-year Iran–Iraq war.^{1,2} Sulphur mustard gas is an extremely dangerous poison that attacks its victims both internally and externally. The symptoms include eye irritation, inflammation and blindness. It also affects the skin and causes itchy redness that leads to blistering. It assaults the respiratory system by stripping off the mucous membrane of the bronchial tubes, causing a hoarse throat, shortness of breath, coughing and a choking sensation. The digestive system is also affected with abdominal pain, diarrhoea, fever and vomiting.³ Once exposed to a certain dosage, mustard gas can kill its victim in 4–5 weeks. For many, however, it leaves a lifetime of physical disability.⁴

Approximately 20 000 Iranian troops and civilians were killed by mustard gas attacks during the Iran–Iraq war, and another 80 000 were injured. This is about a quarter of the number of deaths caused by chemical weapons during the First World War.⁵ The casualties of mustard gas was especially pronounced for the soldiers and civilians in the border towns and villages of the north-western region of Iran.⁶

Approximately 34 000 Iranians sustained exposure to this chemical warfare agent,^{7,8} which is now costing the nation's healthcare system about \$37 million annually.⁹ Sardasht is a small city in the West Azarbaijan province in north-western Iran, 10 km from the Iran–Iraqi border. This city was exposed to both chemical and non-chemical bombardments (60 times) during the Iran–Iraq war. In June 1987, this Kurdish town was attacked with four 250 kg

sulphur mustard warheads that exploded in the centre of the town, injuring approximately 4500 residents.¹⁰

Several studies have investigated the physical health consequences of exposure to mustard gas.^{1,8,11} However, there is little research evaluating the mental health outcomes of such exposure. In a sample of Second World War veterans who were exposed to mustard gas, nearly a third met the criteria for full current post-traumatic stress disorder (PTSD) 50 years after their exposure.^{12–15} Tavalaei *et al* reported PTSD in 90% of Iranian chemical warfare victims.⁷ Romano *et al* demonstrated anxiety disorders in 57% of soldiers exposed to chemical and biological agents.¹⁶ Anxiety disorders were reported to be more frequent in Iranian chemical warfare victims in comparison with other disabled veterans.^{17–19} Post-traumatic stress disorder not only affects the quality of life of war veterans but also creates a huge burden for their caregivers and families.²⁰ Several studies have pointed to the mental health problems in the family members of disabled veterans.²¹ Secondary traumatization refers to a therapist's reactions to clients' often painful and graphic traumatic experiences.²² The experience of secondary trauma, or the spread of trauma from the victim to those close to the victim,²³ has been reported by mental health clinicians²⁴ and healthcare workers who are involved with the care of traumatised individuals, including victims of child abuse,²⁵ interpersonal violence,^{26,27} torture²⁸ and large-scale disasters.^{29–31} Compassion fatigue or secondary traumatic stress are two other terms that refer to the psychogenic reactions to the traumatic experience of a person who is important to us (Box 1).^{32,33}

Psychological and physical symptoms of exposure to secondary trauma are similar to those experienced by people who have been directly affected by a traumatic event including nightmares about the victim, insomnia, irritability, loss of emotions, fatigue,³⁴ headache, hearing problems, predisposition to infectious diseases and substance misuse.^{35,36} The experience of caregiver burden has been investigated extensively.^{34,37–45} However, the prevalence of secondary PTSD among wives of chemical warfare victims has not been studied. Female spouses of war

victims, because of their close contact with their husbands, are among the groups at-risk for secondary traumatic stress.⁴⁶ Often the role of such female spouses is to preserve family stability and regulate family functioning, which subject them to extra pressure.³⁶ In Iran, it is within the expected cultural norm that the male victims of chemical warfare live at home with the assistance of their wives. The need for respite for these wives is often not recognised until their own health begins to deteriorate. The mental well-being and physical strength of these wives is essential for providing ongoing care in the home and avoiding or postponing institutionalisation. Therefore, identification of secondary PTSD symptoms among these female spouses should be considered in the development of strategies to offset caregiver burden.

This study aimed to compare the prevalence of PTSD symptoms among the husbands in case and control groups; to compare the prevalence of secondary PTSD symptoms among the wives in case and control groups; and to identify if there is an association between the PTSD symptoms of the couples in the case group. We hypothesised that there would be a higher level of PTSD symptoms among husbands in the case group than in the control group; there would be a higher level of secondary PTSD symptoms among the wives in the case group than in the control group; and there would be a direct association between the PTSD symptoms of the husbands and wives in the case group.

Method

Participants

This was a cross-sectional case–control study. For the selection of cases, study staff reviewed all the available records in the Foundation of Martyrs and Veterans Affairs in Sardasht to identify male civilians who were chemical war victims. There were 1336 registered male chemical war victims in Sardasht. They were recruited for the initial screening. The screener included items from the DSM–IV–TR⁴⁷ criteria A (stressor) for PTSD¹⁰ assessing if during exposure to the war: the chemical war victim was confronted with an actual or threat of death or injury; and if the individual expressed feeling of hopelessness and fear. The people who screened positive on both items were recruited for the study along with their wives. Next, the husband–wife couples were screened for participation eligibility based on the following criteria: history of chronic disease or a malignancy; history of chronic diseases or malignancies among other members of the family; presence of any other chemical war victims or disabled persons living with the family. Couples who responded 'no' to all the aforementioned criteria were eligible to take part in the study. Of the 176 case–couples who met study eligibility criteria, 150 (85.2%) agreed to sign an informed consent form and participated in the study. For selection of couples in the control group, systematic random sampling was used and we selected 156 couples from a list of residents in Sardasht. The control couples met the same aforementioned eligibility criteria and were matched with the case couples by age, direct exposure to the destruction and material losses of war as a traumatic life event and indirect exposure

Box 1 Definition of terms

- Secondary post-traumatic stress disorder (PTSD): presenting PTSD-like symptoms (including nightmares, insomnia, irritability, loss of emotions, fatigue, headache etc) without directly have experienced a traumatic event
- Civilian: an ordinary individual who may have or have not been exposed to the chemical warfare during the 8-year Iran and Iraq war
- War victim: any civilian who has been, physically or mentally affected by a war
- Chemical war victim: a civilian male war victim who survived exposure to chemical warfare during the 8-year Iran and Iraq war
- Case group: a husband–wife couple where the husband was a chemical war victim
- Control group: a husband–wife couple where the husband was a civilian who was not exposed to chemical warfare

to socioeconomic disadvantages of war and military drafting of family members and/or friends. The difference between the case and control couples had to do with the exposure of the husband in the case couples to chemical warfare during the Iraq–Iran war.

Outcome measure

We used the Mississippi Scale for Combat-Related PTSD (M–PTSD)⁴⁸ to measure the study outcome variable. The M–PTSD was originally developed by Keane and colleagues⁴⁸ and was later revised by Norris *et al.*⁴⁹ The M–PTSD is a 39-item self-report measure of combat-related PTSD. It takes 10–15 min to administer, and includes items related to: re-experiencing symptoms of the traumatic event, such as intrusive memories and recurrent nightmares, which reflects DSM–IV criterion B for PTSD; engaging in protective reactions, such as avoidance of the stimuli associated with the trauma and emotional numbing, which reflects DSM–IV criterion C for PTSD; and experiencing arousal symptoms, such as startled responses and hypervigilance, which reflects DSM–IV criterion D for PTSD.

Respondents were asked to rate how they felt about each item using 5-point Likert-scale response categories. Responses were summed to provide an index of PTSD-symptom severity score ranging from 39 to 195; a higher score indicating more severe symptoms of PTSD. The original 35-item scale was tested among samples of veterans seeking treatment, and has been shown to have high reliability (Cronbach $\alpha = 0.94$)⁴⁸ and validity.⁵⁰ Goodarzi⁵¹ validated the Persian/Farsi version for the Iranian population (2003) and reported high internal consistency (Cronbach $\alpha = 0.91$) and cross-cultural validity. Keane *et al* reported that a cut-off score of 107 has a sensitivity of 93% and a specificity of 89%.⁴⁸ However, it has been reported that the scale is vulnerable to faking and therefore a cut-off score of 121 has been suggested.⁵² Although the sensitivity of this cut-off score is good (0.95), its specificity is

compromised (0.45). A cut-off score that would optimise both sensitivity and specificity has not been reported.⁵³

The Bonyad-e Janbazan Morbidity Index

The Bonyad-e Janbazan Morbidity Index (www.dolat.ir/NSite/FullStory/?id=189580) is a formal index developed by the Bonyad-e Janbazan Foundation; a national organisation responsible for the social, physical and mental health and welfare of war-induced disabled veterans, civilians, and their immediate families. This index was developed using objective data (i.e. physical symptoms) extracted from the medical charts and/or personal interviews with the chemical war victims. The Morbidity Index is reported as a percentage and determines the veterans' degree of morbidity and disability. Based on this index, chemical war victims who score $\geq 25\%$ are eligible for physical, psychological, social and economic assistance. According to a report by Bonyad-e Janbazan, there are currently 1400 chemical war victims of whom 400 score $\geq 25\%$ on the Morbidity Index. These victims and their families receive medical, social and economic assistance from this organisation.

Statistical analysis

We used SPSS software version 11.5 for Windows to calculate measures of central tendency including mean, median and measures of dispersion such as standard deviation to provide univariate analysis of the study's main variables. In order to test the study hypotheses, we used independent *t*-tests, Pearson's correlation and chi-squared tests. $P \leq 0.05$ was set as the statistically significant level.

Results

In this study we set out to compare the prevalence of PTSD symptoms among the husbands in case and control groups. We anticipated detecting a higher level of PTSD symptoms

Table 1 Mean scores on the Mississippi Scale for Combat-Related PTSD symptoms and its subscales for the husbands (war victims) in the case and control groups

	<i>n</i>	Mean (s.d.)	<i>t</i>	<i>P</i>
Total score			4.80	0.001
Case	148	123.06 (17.19)		
Control	156	112.29 (21.73)		
Frequently haunted by memories			4.33	0.001
Case	150	32.36 (7.32)		
Control	156	28.62 (7.71)		
Problems with personal relationships			4.55	0.001
Case	148	29.54 (7.26)		
Control	156	25.50 (7.18)		
Problems in controlling emotional feelings			2.85	0.005
Case	150	31.52 (4.67)		
Control	156	29.21 (8.79)		
Lack of depression			0.75	0.48
Case	148	29.55 (6.39)		
Control	156	28.94 (8.56)		

PTD, post-traumatic stress disorder.

Table 2 Prevalence of Mississippi Scale for Combat-Related Post-Traumatic Stress Disorder (M-PTSD) symptomatology for wives in case and control groups

Cut-off points on M-PTSD	Case group, <i>n</i> (%) (<i>n</i> = 150)	Control group, <i>n</i> (%) (<i>n</i> = 156)	<i>P</i>
>121	109 (72.6)	55 (35.2)	0.002
>107	139 (92.6)	94 (60.2)	0.009

Table 3 Severity of Mississippi Scale for Combat-Related Post-Traumatic Stress Disorder (M-PTSD) symptoms in the wives in the case and control groups

	M-PTSD score			<i>P</i>
	Mild, <65: <i>n</i> (%)	Moderate, 65–130: <i>n</i> (%)	Severe, >130: <i>n</i> (%)	
Group				0.001
Case	2 (1.4)	140 (96.6)	3 (2.1)	
Control	40 (25.6)	113 (72.4)	3 (1.9)	

among the husbands in the case group than in the control group. Table 1 presents the mean differences for the overall PTSD symptoms in these groups. Husbands in the case group had a significantly higher overall mean score (123.0, s.d. = 17.2) than the husbands in the control group (112.3, s.d. = 21.7; $P < 0.001$, $t = 4.80$). Table 1 also reveals that there are statistically significant ($P < 0.05$) differences between the PTSD subscale mean scores of the husbands in the case group compared with those in the control group ('frequently haunted by memories' 32.4 v. 28.2; 'problems with personal relationships' 29.5 v. 25.5; 'problems in controlling emotional feelings' 31.5 v. 29.1; and 'lack of depression' 29.5 v. 28.9 (Table 1)).

We also investigated whether the wives in the case group would report higher levels of PTSD symptoms compared with their counterparts in the control group. Using chi-squared tests of association, Tables 2 and 3 demonstrate that there are differences between the two groups across three sets of cut-off points for PTSD (<120 and ≥ 121 ; <106 and ≥ 107 , <65, 65–130 and >130). We used different sets of cut-off points to factor in the vulnerability of M-PTSD to faking reported in the literature.⁵² Across all cut-off points, wives in the case group demonstrated higher rates of PTSD symptoms than their counterparts in the control group, and the difference between the two groups was statistically significant. Using the chi-squared test of association for the <120 and ≥ 121 cut-off score, the rates between the case and control groups were 72.6% v. 35.2% ($P < 0.002$). For the <106 and ≥ 107 cut-off score, 92% of those in the case group reported PTSD symptoms, whereas 60.2% of the control group reported such symptoms (Table 2).

For the current study, a PTSD score of ≤ 65 was labelled as 'mild', 65–130 as 'moderate', and >130 as 'severe' symptoms. Nearly all the wives in the case group reported 'moderate' PTSD symptoms (96.6%). For the control group, this rate was 72.4%. The difference between the two groups was statistically significant ($P < 0.001$) (Table 3).

Table 4 shows the mean scores for the overall PTSD symptoms and its subscales for wives in both groups. Wives in the case group had a significantly higher overall mean

score (128.68, s.d. = 12.67) than their counterparts in the control group (111.27, s.d. = 21.21; $P < 0.001$, $t = 8.71$). Similarly, we detected significantly ($P < 0.001$) higher mean scores for all the M-PTSD subscales among the wives in the case group in comparison with the control group: 'frequently haunted by memories' 35.4 v. 29.1; 'problems in personal relationships' 29.3 v. 26.4; 'problems in controlling emotional feelings' 32.9 v. 28.8; and 'lack of depression' 31.1 v. 26.9 (Table 4).

We also expected to detect a direct association between the husbands' report of PTSD symptoms and that of their wives in the case group. However, there was none based on the overall PTSD score ($P = 0.274$, correlation coefficient 0.092). Furthermore, we could not detect any statistically significant association between the overall PTSD scores of the wives and the disability scores of their husbands calculated based on the Bonyad-e Janbazan Morbidity Index, as described in the Method (Table 5).

Discussion

Main findings

Our study showed that male civilians who were directly exposed to chemical warfare during the Iraq–Iran war had higher level of PTSD symptoms compared with their non-exposed counterparts. Tavalaei *et al* also reported that the prevalence of PTSD symptoms among Iranian chemical warfare victims was as high as 90%.⁷ Several other studies have demonstrated high rates of PTSD symptoms among war veterans.^{10,12,14,15} This is an important finding since PTSD has been reported to be a risk factor for developing dementia,⁵⁴ diminished quality of life^{55,56} problems readjusting to community life;⁵⁷ and more alcohol consumption and illicit drug use.⁵⁶ Coordinated treatment and policy efforts and intervention procedures could improve the functioning and well-being of chemical war victims. Moreover, clinicians should be alert that chemical war victims with PTSD could suffer from comorbid medical problems and undertake health-compromising risky behaviours. Therefore, they should recommend regular

Table 4 Mean scores on the Mississippi Scale for Combat-Related Post-Traumatic Stress Disorder (M-PTSD) symptoms and its subscales in wives in the case and control groups

	<i>n</i>	Mean (s.d.)	<i>t</i>	<i>P</i>
Overall score			8.71	<0.001
Case	145	128.68 (12.67)		
Control	156	111.27 (21.21)		
Frequently haunted by memories			8.19	<0.001
Case	147	35.42 (5.89)		
Control	156	29.14 (7.39)		
Problems with personal relationships			4.18	<0.001
Case	148	29.35 (3.95)		
Control	156	26.39 (7.81)		
Problem in controlling emotional feelings			5.47	<0.001
Case	150	32.95 (3.80)		
Control	156	28.85 (8.49)		
Lack of depression			5.42	<0.001
Case	145	31.08 (4.74)		
Control	156	26.87 (8.37)		

physical check-ups, offer regular screening for substance misuse and provide adequate referrals.⁵⁸

As demonstrated in the results, the rate and intensity of PTSD symptoms among wives in the case group were significantly higher than those in the wives in the control group where husbands were not affected by chemical warfare. This pattern was evident by higher representation of wives in the case group across cut-off points (>121 and >107; $P < 0.5$). Moreover, nearly all the wives in the case group (96.6%) reported suffering from moderate or severe PTSD symptoms. In the control group, this rate was 72.4%, and the difference between the two groups was statistically significant ($P < 0.5$). Also, across all the PTSD symptom subscales, including 'frequently haunted by memories', 'problems in personal relationships', 'inability to control emotional feelings' and 'lack of depression', the mean scores for the PTSD symptoms of the wives in the case group were higher than the mean scores of their counterparts in the control group ($P < 0.5$) (Table 3). These findings corroborate previous empirical results that report a high level of secondary PTSD among the spouses of warfare victims.⁵⁹ It also adds to the existing knowledge by highlighting the extra burden that the wives of chemical warfare victims endure. The physical and psychological consequences of these burdens, if left uncontrolled or unchecked, can have significant adverse health consequences not only for the wife as a caregiver but also for the patient (i.e. husband) if and when proper caregiving is threatened. Therefore, identification of the level and intensity of secondary PTSD symptoms among wives of chemical war victims should be the first step towards the development of strategies to offset caregiver burden among this group. In this respect, primary care physicians should keep wives of chemical war victims under their constant attention, regularly screen them for undetected mental, emotional and physical stress, and provide them with proper referrals as needed. Home-based interventions can provide creative and culturally accepted options to overcome the burden of care for this population. It could also be of value in lowering medical costs and sustaining effective care for chemical war victims and their wives.

Furthermore, family psychologists who provide care to chemical war victims must also address the trauma experienced by these individuals' wives. They should assist both of them so that they recover from their ordeals together.³⁴ The salience of effective social supports and the benefits of empowering wives of war victims to manage the sociopsychological burdens of caregiving are included among the interventions suggested.⁶⁰ These types of therapeutically induced interventions may provide a buffer against relationship distress caused by caregiver burden.³⁹

Nevertheless, it is important to note the high rate of PTSD-like symptoms in the wives of non-affected husbands. This could be attributed to these women's experiences of the war's brutality and the overall life-threatening situation in Sardasht during the war. As was mentioned earlier, all the participants in the study were civilians (residents) of Sardasht who were exposed to extensive bombardments during the Iraq–Iran war and its direct and indirect socioeconomic consequences, with the exception that husbands in the case group were exposed to chemical warfare. The high rate of PTSD-like symptoms among the wives in the control group therefore could be the long-lasting result of a war that left women living in Sardasht vulnerable to the symptoms of PTSD. Further studies are needed to identify other sociopsychological characteristics

Table 5 Distribution of Mississippi Scale for Combat-Related Post-Traumatic Stress Disorder (M-PTSD) scores in spouses of chemical warfare victims based on husbands' morbidity percentage according to the Bonyad-e Janbazan Morbidity Index

Husbands' morbidity, %	Wives' M-PTSD score, mean (s.d.)	<i>P</i>
<20	128.01 (1.89)	>0.05
20–30	126.37 (2.12)	
30–40	128.61 (3.11)	
>40	134.52 (3.46)	

of these women and how they may be related to the reporting of PTSD symptoms among women living in Sardasht.

In our study there was no significant relationship between the PTSD symptoms of the wives and that of their husbands in the case group. This finding is similar to the results of Al-Turkait *et al*⁶⁰ who studied PTSD among the wives of military men who fought during the first Gulf War in Kuwait and found no association between the level of PTSD in the wives and their husbands. We also did not detect any association between the husbands' degree of morbidity and disability (measured by the Bonyad-e Janbazan Morbidity Index) and the PTSD symptoms of their wives. We tested this secondary hypothesis because findings from the caregiver literature suggest that the level of PTSD symptoms among caregivers most likely depends on the functional status and cognitive function of the individual they are providing care for.^{61–63} Dekel *et al*³⁷ have suggested that the level of distress among caregivers is more closely associated with perceived caregiver burden than with the level of the primary individual's physical impairment.

Perception of caregiver burden in a country such as Iran where the help-seeking journey starts at home could explain the lack of association between chemical war victims' PTSD symptoms and those of their wives. In Iran, it is within the cultural norms and expectations that women provide proper care for their sick husbands or any other members of the family. Therefore, although providing continued home-care for a chemical war victim can be stressful and straining, for some women this may increase their sense of self-satisfaction, self-efficacy and confidence knowing that they have fulfilled the expected 'female role'. The lack of association could also be reflective of the Islamic beliefs in the lives of wives/caregivers who participated in this study. The spiritual beliefs of these women could have provided them with a coping strategy that disassociates their mental health with that of the husbands. Further imperial investigations are needed to identify protective characteristics in women who care for their husbands who are chemical war victims including spirituality and self-efficacy.

Limitations

This study has several limitations and therefore the results should be interpreted with caution. First, study data were cross-sectional, limiting our ability to offer any causal inferences about the role of variables that were statistically significant. Second, data for this study were self-reported, therefore subject to response bias. Third, our data lack measures of different physical consequences of exposure to chemical agents in chemical war victims. The severity of the chemical war victims' physical problems was measured only by the 'disability percentage', which had been determined by the Bonyad-e Janbazan Morbidity Index.

However, our study is the first to focus on the secondary PTSD symptoms of the wives of chemical war victims and its association with the PTSD symptoms of their husbands. In this study, we were unable to prove the proposed association between the PTSD symptoms of the chemical war victims and their wives in the case group

beyond the probable role of caregiver burden. As mentioned earlier, this could be attributed to a pre-existing mental and psychological vulnerability among the wives because of their exposure to the war. Further investigations are needed to include data about the pre-existing psychological problems of wives in the analysis and interpretation process. These investigations may also benefit from a longitudinal design, inclusion of multi-item risk and protective predictors and the inclusion of social-related variables.

Implications

In our study, husbands (chemical war victims) in the case group had a significantly higher overall PTSD mean score than the husbands in the control group. Furthermore, wives of chemical war victims demonstrated higher rates of PTSD symptoms than the wives in the control group, and the difference between the two groups was statistically significant. There was no statistically significant association between the overall PTSD score of the husbands in the case group with the PTSD scores of their wives. Studies are needed to explore the characteristics of wives of chemical war victims including their physical, psychological, religious and coping styles, and how they change over time. Results of these studies can help to better understand these and other factors contributing to increased secondary PTSD symptoms or factors that buffer against it. Furthermore, interventions that coordinate clinical care and home-based care for chemical war victims are needed. Proper outcome evaluations of these and other relevant efforts are needed in order to develop more effective caregiver interventions for this population.

About the authors

Khodabakhsh Ahmadi (PhD) is an associated professor at the Behavioral Sciences Research Center at the Baqiatallah University of Medical Sciences in Tehran, Iran. **Mahmood Reshadatjoo** (MD) is a research assistant at the Students' Research Committee at Urmia University of Medical Sciences in Urmia, Iran. **GholamReza Karami** (MD) is an assistant professor at the Baqiatallah University of Medical Sciences in Tehran, Iran. **Nariman Sephehvand** (MD) is a research fellow at the National Institute of Health Research at Tehran University of Medical Sciences in Tehran, Iran. **Pegah Ahmaddi** (MD) is a research assistant at the Students' Research Committee at Urmia University of Medical Sciences in Urmia, Iran. **Shahzad Bazargan-Hejazi** (PhD) is at the department of psychiatry, Charles Drew University of Medicine and Science, and Department of Psychiatry and Biobehavioral Sciences, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, USA.

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Usefulness of reader feedback on the Royal College of Psychiatrists' public information leaflets

Martin Briscoe,^{1,2} Simon Briscoe,³ Philip Timms,^{2,4} Ros Ramsay^{2,4}

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¹Devon Partnership NHS Trust; ²Royal College of Psychiatrists Public Education Editorial Board; ³Lancashire Teaching Hospitals NHS Foundation Trust; ⁴South London and Maudsley NHS Foundation Trust

Correspondence to Dr M. Briscoe (drmmbriscoe@gmail.com)

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Aims and method To describe the process for reader feedback on the Royal College of Psychiatrists' online public information leaflets, to report the findings of a retrospective analysis of feedback received over a 14-month period, and to discuss the value of feedback, particularly in relation to the Information Standard quality mark introduced by the Department of Health.

Results We received 38 700 completed feedback forms during the period under analysis. We derived scores from the feedback forms, which enabled us to identify those that should be prioritised for review. Written comments from readers highlighted specific areas of the leaflets that required further work.

Clinical implications The development of our public mental health information can be guided using feedback from our readers.

Declaration of interest M.B., P.T. and R.R. are involved in the production and development of the College's online and printed mental health information leaflets.

Providing patient information has become increasingly recognised as an important part of clinical practice. Without it, informed choice about treatments is not possible. Unfortunately, much patient information is written in complex language and is poorly presented.¹

In an attempt to improve patient information, the Department of Health recently established the Information Standard quality mark (www.theinformationstandard.org). This mark signposts trustworthy information. It is awarded to organisations after assessing their editorial and review

processes, and comparing a small sample of their leaflets against a modified 29-item version of the International Patient Decision Aids Standards Instrument checklist.² The Royal College of Psychiatrists was involved in the pilot phase of this project and received its accreditation in 2009.

The College website (www.rcpsych.ac.uk) has hosted patient information resources for over 10 years. The website has become a leading source of public mental health information in the UK. We know this because the leaflets are ranked highly by Google, the most popular search engine in the UK. A search of mental health keywords such as ‘depression’, ‘anorexia’ and ‘schizophrenia’ returns the leaflets in the top five search results. In addition, at the time of writing, the website is ranked higher in terms of popularity than many of the leading main mental health charity websites in the UK, including Mind, Sane, Rethink, Depression Alliance and the Mental Health Foundation (www.alexa.com).

The public information section currently has 113 mental health information leaflets, with over 150 translations into Arabic, Bengali, Persian, Urdu, Chinese, Hindi, Greek, Spanish, French, Russian, Polish, Gujarati, Punjabi and Welsh. The 113 leaflets are divided into four categories:

- *Help is at Hand* leaflets, which contain up to 12 pages of in-depth information about mental health conditions;
- *Keyfacts* leaflets, which are briefer, two-page overviews of the same conditions;
- *Changing Minds* leaflets, which are designed to challenge stigma;
- *Mental Health and Growing Up* (MHGU) leaflets, which cover mental health problems in young people.

The College produced paper leaflets for over 10 years before the website was developed, but it had difficulty evaluating the leaflets and gathering feedback. The website provided an opportunity to find out what our readers thought of the leaflets and to collate feedback to guide their further development. Against this background, this paper reviews the feedback received from our readers between 1 September 2008 and 31 October 2009.

Method

Readers are offered the opportunity to complete a feedback form at the end of each leaflet. There are three parts to the form:

- information about the reader
- free-text comments
- a five-point scale to rate the readability, usefulness, respectfulness and design of the leaflet (Fig. 1).

The feedback forms are emailed to the College and the results automatically collated and stored in a database.

Results

Website visits


During the period under analysis there were 3 378 000 visits to the College website by 2 247 000 people from more than 222 countries. The highest visiting countries can be seen in Table 1. The country of origin could not be identified for 20 000 visitors (approximately 0.5%).

On average each visitor looked at three pages on the website, resulting in about 10 million page views. The public information section is the most popular area of the website, accounting for about 40% of these visits.

Feedback forms

We received 37 800 feedback forms – approximately one form for every 80 visitors to a leaflet. Forms that were completed only partially were excluded from the analysis. Leaflets with fewer than 20 completed feedback forms were excluded to ensure that average scores for each leaflet were based on a significant number of responses. We also excluded feedback on foreign-language leaflets.

Table 2 shows the overall number of leaflets in each category; the number of leaflets with 20 or more replies included in the analysis; the number of feedback forms received in each category; and the number of complete feedback forms included in the analysis. The final column gives the overall average leaflet score for each category. This is calculated by averaging the scores for the four modalities

Tell us what you think of this leaflet!! 

Please answer the following questions and press 'submit' to send your answers OR E-mail your responses to dhart@rcpsych.ac.uk
 On each line, click on the mark which most closely reflects how you feel about the statement in the left hand column.
 Your answers will help us to make this leaflet more useful - please try to rate every item.

This leaflet is:	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
Readable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respectful, does not talk down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Well designed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fig 1 Example of feedback form.

Country	Visits, <i>n</i>	% of total visits
UK	2 500 000	73
USA	257 000	7
Canada	80 000	2
Ireland	80 000	2
Australia	77 000	2
India	30 000	1
Iran	24 000	0.5
Other (including unknown)	330 000	12.5

(readable, useful, respectful, well-designed) in the feedback form. The modalities are measured on a scale of 1 (lowest) to 5 (highest).

These figures show that the main leaflets are by far the most popular. This is probably because they are ranked very highly on Google. During the period under analysis, the most popular leaflet was on cognitive-behavioural therapy (CBT), attracting over 385 000 readers. During this time, Google ranked this leaflet in first place on a search for 'CBT' or 'cognitive behavioural therapy'. The second most popular leaflet was on antidepressants, which was also ranked in first place by Google.

The overall average scores for each leaflet category are high (4.38–4.55 out of a maximum of 5), suggesting that the leaflets are well received.

Demographics

The age breakdown of the people submitting feedback forms can be seen in Fig. 2 (4% of responders did not indicate their age). As might be expected, the MHGU leaflets attract young readers: 20% are aged 16 years or under. The *Changing Minds* leaflets also attract young readers: 28%

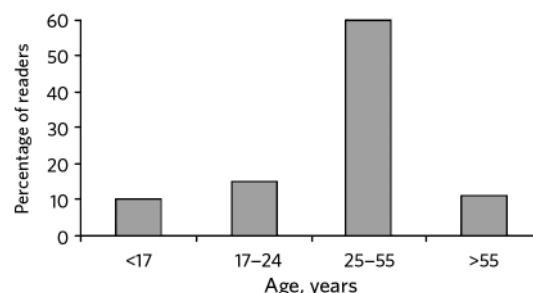


Fig 2 Age of readers.

are aged 16 years or younger and 29% are aged 17–24 years. This could be because the leaflets are short and written in a direct and provocative style.

Overall, 25–38% of readers describe themselves as patients, about 15% as health professionals and 15% as students. The remainder are carers, relatives or friends of a patient.

Individual leaflets

To measure the popularity of individual leaflets within the four categories, we ranked each leaflet according to its average score. Table 3 shows the results for the four highest scoring and four lowest scoring leaflets.

The lowest scoring leaflets are about issues that attract controversy in the public domain. This controversy may partly account for their higher than average share of negative free-text feedback, as described in the next section. The low scores encouraged us to revisit these titles to see whether we can improve them.

Analysis of free-text feedback

We also undertook a simple qualitative analysis of the free-text responses for a number of leaflets. For the purposes of

Leaflet category	Leaflets, <i>n</i>	Leaflets included in analysis, <i>n</i>	Feedback forms received, <i>n</i>	Feedback forms included in analysis, <i>n</i>	Average score (out of 5)
Main	52	51	26 355	17 797	4.55
Keyfacts	16	13	1830	1222	4.54
Changing Minds	7	7	1968	1546	4.48
Mental Health and Growing Up	38	33	3943	2237	4.38

	Leaflet	Leaflet category	Feedback forms, <i>n</i>	Mean leaflet score (mean category score)
Highest scoring	Post-traumatic stress disorder	Main	1108	4.75 (4.55)
	Obsessive-compulsive disorder	Main	287	4.75 (4.55)
	Bipolar disorder	Keyfacts	115	4.74 (4.54)
	Physical activity	Main	136	4.73 (4.55)
Lowest scoring	Anorexia and bulimia	Changing Minds	968	4.03 (4.48)
	Alcohol and depression	Main	280	3.72 (4.55)
	Drugs and alcohol	Mental Health and Growing Up	58	3.72 (4.38)

this paper, we focused on the two highest scoring main leaflets ('post-traumatic stress disorder (PTSD)' and 'obsessive-compulsive disorder (OCD)') and the two lowest scoring main leaflets ('Cannabis and mental health' and 'Alcohol and depression'). For the highest scoring leaflets, 54% provided a simple commendation such as 'great leaflet'; 33% provided some autobiographical information about their problem; 7% asked a question; 6% gave a constructive suggestion; 4% said they intended to use the leaflet in their work; and about 2.5% left a negative or abusive comment. The lowest scoring leaflets were just as likely as the highest scoring leaflets to receive commendations but more than twice as likely to receive a negative comment (6% *v.* 2.5%).

The constructive criticisms are particularly useful in helping us to identify specific ways in which to improve the leaflets (Box 1).

Discussion

The introduction of the Information Standard quality mark should lead to an improvement in the reliability of patient information among participating organisations. However, it does not necessarily follow that leaflets conforming to this standard will be well received by the public. The only way to assess the reception of a leaflet is to ask the readership.

The quantitative feedback enables us to rank the leaflets and to determine which leaflets need more attention. The qualitative feedback provides constructive advice, suggestions and challenges that help us to identify specific areas for rewriting or fine-tuning. Because the Spearman's correlation between the modalities on the feedback form is high (0.72–0.96), we could simplify the form and use a single score, such as the five-star rating system used by Amazon.com. In the future we would like to display this rating alongside the leaflets so that readers can see at a glance how previous readers have rated them.

Our current findings suggest that reader feedback provides invaluable guidance about the substance and presentation of our public mental health information. This feedback complements the Information Standard quality mark, which is focused mainly on editorial, review and production processes.

Box 1 Examples of commendation, constructive and negative responses

Alcohol and depression leaflet

- Commendation: 'I strongly agree with everything you have commented on and have taken many points into consideration. I really hope I can learn from this leaflet.'
- Constructive: 'My only criticism of your leaflet is that it does not address the social pressure to drink which is ingrained in British culture. I'd love to go out for "a" drink but in practice I end up drinking up to 8 units in one sitting.'
- Constructive: 'Could use some pictures for a friendlier feel.'
- Negative: 'This information is appalling (sic) and of terrible quality. Alcoholics know what is wrong and why they need SOLUTIONS.'

Cannabis and mental health leaflet

- Commendation: 'This was really really useful and opened my eyes to a lot of things I didn't realise.'
- Constructive: 'More subheadings would be useful for young people – perhaps even illustrations. It has quite a high reading age.'
- Constructive: 'It would need to have more visual diagrams and probably less slang (which can quickly get out of date).'
- Negative: 'Negative and typical of official sources.'

About the authors

Martin Briscoe is Consultant Psychiatrist at the Devon Partnership NHS Trust, Editor of the Royal College of Psychiatrists' website, and a member of the Royal College of Psychiatrists' Public Education Editorial Board. **Simon Briscoe** is Assistant Clinical Librarian at the Lancashire Teaching Hospitals NHS Foundation Trust. **Philip Timms** is Consultant Psychiatrist at the South London and Maudsley NHS Foundation Trust and Chair of the Royal College of Psychiatrists' Public Education Editorial Board. **Ros Ramsay** is Consultant Psychiatrist at the South London and Maudsley NHS Foundation Trust and a member of Royal College of Psychiatrists' Public Education Editorial Board.

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