The challenges experienced by Iranian war veterans living with chemical warfare poisoning: a descriptive, exploratory study

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This exploratory, descriptive study investigates the experiences of Iranian war veterans living with chronic disease acquired as a result of chemical warfare. Sulphur mustard (SM) is considered one of the most important agents of chemical warfare and was widely used during the Iran–Iraq conflict in 1980–1988. There are approximately 100 000 Iranian SM casualties who suffer from serious long-term progressive health problems involving their respiratory organs, eyes and skin. Seventeen male Iranian war veterans aged between 30 and 59 years and four victims’ family members participated in the study. Data was generated during individual in-depth interviews that used open-ended questions. Grounded theory techniques, including the constant comparative method of concurrent data generation and analysis, were employed in the analysis of data. Preliminary results indicate two main thematic categories: social isolation and physical disability. It is argued that a lack of knowledge about the outcomes of SM poisoning, physical restrictions and difficulty in adjusting socially decreases war veterans’ functional capacity and levels of independence.

Keywords: chemical warfare agents, sulphur mustard, poison, chronic illness, qualitative research, nursing.

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Introduction

Sulphur mustard (SM) is a significant chemical military warfare agent that has been widely employed in the past century. It is estimated that over 1 200 000 soldiers were poisoned with SM during World War I (WWI) and about 400 000 of this number required protracted treatment (1). SM is often called ‘king of the battle gases’ (2) and remains the chemical weapon of choice in modern tactical warfare (3). The only other major use of SM since WWI occurred during the Iran–Iraq war in the 1980s. Deploying SM as a weapon during this conflict was a direct violation of the Geneva Protocol of 1925 (4, 5) and resulted in the tragic deaths of thousands of soldiers and civilians, with more than 100 000 casualties including war veterans now requiring ongoing medical assistance (6). This article reports the results of a descriptive, exploratory study that examines the experiences of Iranian war veterans living with health problems resulting from exposure to SM during the Iran–Iraq conflict. Thematic analysis of the data identifies a typology of disabilities including social and physical disability. Each of these will be explained and illustrated using excerpts from the data. Manifestations of the typology overall will then be discussed in relation to the literature.

There is a dearth of research findings that discuss the experiences of Iranian war veterans. We do not know what everyday life is like for veterans who have been poisoned by SM. Rather than assuming that healthcare professionals know best; this study seeks to describe the experiences of Iranian war veterans living with chemical warfare effects thereby providing greater understanding and insight into their world.

Background

There is an identified gap in the literature about the experiences of people living with SM toxicity and the effects this
has on their lives. The Iran–Iraq war commenced after Iraqi attacks on Khuzestan on 22 September 1980 and continued until 1988. Iraqis started to use chemical warfare poisons in 1982 (7). Different chemical agents, such as nerve agents and mustard gases, were widely used in this war.

Mustards are vesicant agents; exposure in high doses causes blistering of skin and mucous membranes, damage to the eyes and the respiratory tract (8). In addition, reproductive and developmental toxicity, gastrointestinal and haematological effects and some cancers, have been found to be associated with exposure to these chemicals (6, 9). Symptoms experienced by people who have been exposed to SM include severely dry skin (10), delayed dermatitis (11) and impairment of natural killer cells (12). Commonly, complications affect the lungs (95%), peripheral nerves (77.5%), skin (75%) and eyes (65%) for up to 20 years after exposure to SM (13).

One-third of the 100 000 Iranian SM casualties from the Iran–Iraq conflict still alive today are suffering from chronic long-term progressive health problems. Most survivors are also suffering from significant psychological disorders including a progressive sense of alienation, depression, loss of family unity, posttraumatic stress disorder and anxiety (14). Chemical weapons victims suffer from irreversible and deteriorating health status (15). The results of recent interpretive sociological studies of chronic illness suggest the need for a multidimensional view of chronic illness impact on everyday life (16).

Iranian casualties of SM toxicity are mainly middle-aged men who are attempting to be active members of society while also living with potentially life-threatening, long-term diseases – the consequences of which impacts on their daily activities, resulting in a poor quality of life (17). Chronic poisoning complications were initially missed in this group because of a lack of awareness of the potential problem amongst most clinicians (18).

Currently, there is no effective treatment for toxicity from SM and despite numerous studies; the long-term effects of SM have not been clearly identified. There is little information regarding the experiences of those who live with chronic diseases and literature relating to the topic is mainly focused on the disease process. Patient management and compliance with prescribed interventional therapies are topics that occupy much of the literature.

Methodology and research design

Underpinned by the tradition of qualitative research, descriptive exploratory research designs are useful to investigate topics about which little is known (19). Using an interpretive lens, this study seeks to describe the experiences of Iranian war veterans living with chemical warfare effects.

Methods used to analyse the data were adopted from grounded theory and include concurrent data generation and analysis, constant comparison of data and the identification of in vivo codes (19). Data generated with participants were transcribed, coded and then thematically analysed. Constant comparison of data occurred across the data set, both within and between individual transcripts in order to integrate the themes identified in this paper.

Lincoln and Guba (20) argue that the rigour of qualitative research can be judged using the following criteria: auditability, confirmability, authenticity and transferability. In this study, the primary researcher used reflective memos to develop an audit trail of decisions made during the research process (21). This included his personal beliefs and assumptions about the research topic, the culture of Islam and the position of the participants in relation to himself. Using expert informants who considered the transcripts in relation to the analysis developed by the primary researcher confirmed the analysis presented in this article. Authenticity of the study is tied to the use of participant’s words as evidence for the analysis that follows. While the transferability of findings, lies with the reader’s understanding of the analysis presented and their sense of fit and grab with their own situation (22).

Participant recruitment

Participants were selected using a purposive sampling technique of Iranian chemical warfare poisoned veterans. Inclusion criterion was: having exposure to SM following participating in the Iran–Iraq conflict, that had been documented by the Foundation of Martyrs and Veterans Affairs. The Foundation was established in order to honour and glorify the martyrs, wounded veterans, self-sacrificers and their families. Family member of participants were also interviewed about their observations of the effects of SM poisoning had on their husband or father. Participants were selected using maximum variation sampling technique (19) to reflect different ages, range of disease severity and years after initial exposure. The selection process ensured a heterogeneous sample (Table 1) to maximize variation across the sum of the data set.

Participants were recruited through the Foundation of Martyrs and Veterans Affairs, and hospitals for veterans in various Iranian cities. Following approval to conduct the study in each hospital, eligible participants were retrospectively identified by the principle researcher from electronic medical records, or by respiratory nurses working in each hospital. Seventeen war veterans, all males, and four family members (two children and two wives) consented to participate in the study.

Ethical considerations

The Ethics Committee of Medical University of Isfahan approved the study. Veterans who met the inclusion criteria were provided with an explanatory statement that
outlined the aims of the research and explained to participants that they had the option of discontinuing participation at any time without the need to provide a reason. They were also informed that the data generated would be included in the principle researcher’s thesis and that all material would be treated confidentially. If having read the explanatory statement they consented to participate in the study, a written consent form was signed prior to interview.

**Data collection**

Face-to-face interviews were conducted with each participant, either in their home or work place. The interviews lasted from 1 to 3 hours, were audio-taped and subsequently transcribed verbatim. Even though the researcher had only planned to talk with participants for up to 1 hour, some participants were unwilling to disengage after that period of time and so their interviews were longer. Each interview commenced with an opening question, ‘tell me about your symptoms following initial exposure to SM and your experiences to date?’ The participants were then asked about issues encountered and difficulties faced when living with the complications of SM poisoning. A semi-structured interview schedule was used during this process. This schedule was modified between interviews when concurrent analysis revealed directions for additional probing to gain clarification.

**Data analysis**

Concurrent data generation and analysis that included the constant comparative method of data to data and data to categories as described by Strauss and Corbin (19) was undertaken. Analysis was carried out using both an overview analysis and line-by-line coding. Open coding resulted in a large number of single codes that were grouped into categories, which evolved into themes. Although the generated codes and thematic categories tended to be repetitious after the first 14 interviews, the three remaining interviews were analysed for confirmation of the thematic categories already identified thus leading to data saturation. To further ensure the accuracy of the constructed categories two additional researchers reviewed the data. Discrepancies between the analyses were discussed until consensus was reached. Prolonged engagement with the data set assisted in this process. Data generation and analysis was completed over a 12-month time frame. During this time three faculty members not directly involved in the study, but familiar with qualitative research methodologies, reviewed preliminary results of the analysis. They commented on the interpretation of the interview transcripts and questioned points that were unclear; from this process focused questions were asked in subsequent interviews. Additionally, to authenticate emerging codes and thematic categories the findings were discussed with four of the interviewees. Participants felt that the results represented their experiences well and were pleased with the use of their own words in the form of *in vivo* codes. Reflective memos were used to further ensure the auditability and authenticity of this process by which, the researcher’s assumptions and ideas of social context, biases and prejudices to the collection, analysis and interpretation of data affecting the phenomena under investigation were made explicit.

**Results**

Two thematic categories were identified that form a typology of disability experienced by Iranian war veterans exposed to SM with resultant toxicity. The typology includes social isolation and physical disability as outlined in Fig. 1. To protect the identity of participating veterans (V) or their families (F), each interview is identified with a unique number rather than a name.

**Social isolation**

Social isolation is among the most detrimental and distressing consequences of SM poisoning. Participants as
social beings experience social isolation and loneliness as a consequence of diminished social and physical activity. The thematic category of social isolation includes four interdependent characteristics: stigmatization, relationship decline, lack of information and feeling ‘decayed inside’.

Participants believe they are treated unfairly by members of the community who perceive that they have an infectious disease that is contagious. Symptoms of SM toxicity such as bleeding blisters, coughing and feeling itchy may lead to feeling stigmatized both in the community and their work places:

I am worried about others thoughts about me, while I am in a meeting especially as I get hacking cough and so [others] may not to sit down near me... (V3).

In small communities, such as villages, the experience of feeling stigmatized is more pronounced, with myths about the effects of SM toxicity influencing the way that others perceived the participants:

When I got married, there was hearsay I couldn’t have any children because of chemical warfare poisoning but thank God I have three children already (V3).

Sometimes they (people) think that I have got tuberculosis. …they say me you must change your room, if you don’t concern yourself, be worry about your kids, It is better to live in two separate rooms (V9).

Sulphur mustard exposure sometimes causes symptoms similar to chronic obstructive pulmonary disease such as coughing. Participants identified coughing as contributing to being stigmatized. They suggested that coughing is noisy causing people take notice:

Phlegm, cough, especially when it prolongs, draw people’s attention then I try to be less on display (V2).

Participants argued that fighting in the war was been consistent with their religious beliefs and because of this, they are of the opinion that it is not for them to draw attention to themselves, or be seen to make a profit from the chronic illnesses that beset them after being exposed to SM. Not disclosing their illness as a form of explanation for distressing symptoms such as an ongoing cough becomes a demonstration of their humble devotion to God:

Veterans who were faithful to God didn’t disclose their disease for religious issues; they didn’t go to war for making money or for ambitious of position (V11).

The illness concealment influences social encounters and makes new connections hard to obtain. The willingness to be unnoticed separate their life worlds, resulting in disadvantages like lessened and impaired social interactions and social isolation:

I prefer not to explain my illness to new acquaintances and don’t like to commence communication with people who don’t know me (V11).

For all participants, ongoing complications from exposure to chemical warfare negatively influence their relationships both with their families and others that they interact with in their activities of daily living:

I have too much phlegm and can’t stand up any crowds. I can’t go anywhere, eat anything, fried food, pickle…these foods increase phlegm and breath shortness. If someone smokes I go out and don’t ask him to not smoke because I don’t want to bother him (V5).

Most participants also require access to specialized equipment for mobility and assistance with breathing. Limited access to equipment causes frustration and also contributes to relationship breakdown and social isolation:

I can’t go to village to visit my family unless there are portable oxygen and a car with air conditioning...You have to retain phlegm to clean it at once, finally if there is not Kleenex or garbage bag you must clean it by your clothes, hand, parts of your body because of the increasing pressure [ of mucus] (V15).

Often retired war veterans were important and effective people before acquiring a disability as a result of SM toxicity. These individuals do not like to interact and have relationships with people who do not perceive them as a whole person but rather perceive as being sick. This impacts on other family members because it reduces the amount of contact that participants are willing to have with other members of their immediate family, whose pity they feel even more acutely:

We have little relationship even with close relatives even my or his sisters. He doesn’t like they [relatives] know his pains...He hates while they gaze him with pity, and say oh my God I m just sorry…They have been champion, fought courageously for their nation and values in war. If they are seen sick, debilitated, and weak with pathos, they would feel slighted (F2).

Withdrawing from social life because of an inability to predict health status and therefore plan involvement in social activities contributes to relationship breakdown between participant and their immediate family and friends:

His uncle fell ill, became unconscious and considered probable death last year, he took several drugs for his condition to be ready to present at the probable funeral, but finally he fell ill and couldn’t go to see his relatives (F4).
Managing reclusiveness, depression and the symptoms of chronic illness creates enormous pressure within marital relationships as the burden of supporting war veterans suffering from complications is unrelenting, leading to marital breakdown in some participants:

Our family suffers as we suffer, cough, awful noisy cough at night, shortness of breath if you lie down so not sleep until morning, too much mucus and to be awakened frequently at night to clean, every night, every day... [tears in his eyes] my wife. [pause] abandoned me (V17). Participants are not given adequate information about their illness and available treatments and they have to rely on information that themselves acquire. A lack of information provided by health professionals about expected symptoms and potential intervention therapies also contributes to the sense of social isolation, preventing participants and their families from being able to plan to manage for the future:

They [physicians] didn’t used to explain the disease to us and neither do they. We ourselves have had hypotheses about the disease and discovered our lung has damaged from the disease effects for example shortness of breath...When we go to doctors’ office, crowd, standing in line, finally the doctor only looks down, writes some drugs...I try to not go to doctors’ office unless the disease forces me (V16).

Participants said that some people do not understand their disease because they can appear to be healthy on the outside. The perception of war victims having observable limb injuries is prevalent, leading to a lack of understanding for war veterans suffering from SM toxicity that is not immediately obvious to the naked eye. One participant conjured the image of a healthy red apple, shiny on the outside and yet decayed beneath the surface to describe how he felt about peoples’ misconceptions of his life living with a chronic illness:

They [people] only see my appearance, they see my hand and foot have not be cut off in war and I am not on wheelchair, but they don’t know how much I suffer, we are such a red apple with intact outside but when you peel it see the decayed inside (V10).

**Physical disability**

Physical disability is the presence of chronic disease that causes disruption in activities of daily living, resulting in task performance limitation and dependency. Participants describe difficulties in daily life that are associated with a reduced ability to move around, hampering the performance of everyday activities. Dyspnoea, nervousness, insomnia and feeling tired after mild exertion coupled with frequent hospitalization is symptomatic of this:

If my husband wants to drive, portable oxygen has to be along with him, any barriers should not be in front of him...he could not endure red light or heat (F1).

When I catch cold, should be hospitalized, get aching bones, pneumonia and couldn’t breathe, it takes 20–30 days to heal...I have not calmness at night, cough a lot, have too much mucus, and can’t sleep because of asphyxiation feeling and nervousness, have to awake frequently to drink hot water at night. There is much mucus and my throat becomes dry...Ah even walking 50 m makes me breathless. I used to run 5000 m and go swimming but couldn’t continue after poisoning. A few years ago, I tried to run but at the first 100–200 m, my chest was irritated and my condition became critical (V11).

Participants explain the experience of reductions in their functional status. They are frustrated by this progressive disability that had occurred gradually and steadily and still continues. Some of them pinpoint the time when they could not walk up stairs as an example of this:

He had been poisoned 22 years ago, sometimes cough was the only thing I could remember, he was working as my colleague, step by step, became worsened and worsen. Cough, mucus, and breathing problems increased; now the breathing problems don’t let him even speak well (F2).

Many participants experience a restricted lifestyle and state that they are not able to work as well as they did prior to the onset of symptoms. Most of them were forced to retire from the paid full-time workforce a few years after exposure to SM because of the consequences of living with a chronic disease.

I was a builder, did stucco-work, used to work as much as two workers...after poisoning tried to work again but couldn’t, stucco, dust make the disease worse (V8).

One problem in my job is nervousness. You want to decide, to do in hurry, you will get inconvenienced and nervous quickly by a little obstacle...You have to rest for a while, clean your nose and stop work. It takes time, make a gap and absent-mindedness...I would like to work well but if breath is not coming out you couldn’t work (V3).

Because of their physical disabilities, participants declare that they are now dependent on their family for support. If family members are not available then managing daily living activities becomes difficult:

Our son has to go for military service next month. How can I help my husband when his disease becomes more severe, how can I lift oxygen cylinders? (F3).

Most participants felt shame and a sense of be a burden to their family when they asked them for help to manage their physical disabilities:

They [family] suffer day and night and I’m just shameful of bothering them (V2).

**Discussion**

Findings indicate that exposure to SM results in a compromise in an individual’s health status requiring an
adjustment to patterns of daily living. Bury (23) maintains that individuals who are in disadvantaged circumstances face a life trajectory of ‘biographical disruption’ as a result of life crises and events. The chronically ill face multiple challenges in meeting their daily living needs including preventing medical crises, controlling symptoms, caring out medical regimens, preventing or living with social isolation and adjusting to changes in the course of the disease (24). As Toombs states:

Living with permanent incapacity represents a distinct way of being-in-the-world, a way of being that affects one’s sense of self, one’s relationships with others, one’s ability to interact in (and with) the surrounding world, one’s family and professional life, one’s ability to exercise control and to be autonomous and one’s relationship with one’s body. (25, p. 645)

Social isolation and physical disability are categories identified by this study that are outcomes of SM poisoning. Social isolation can be defined as experiencing barriers that are isolating and that result in feelings of exclusion from full participation as an active member of society (26). People who have a physical disability experience social challenges including stigma, discrimination and social exclusion (27). Persons who are afflicted with chronic illness may also be stigmatized by those who are not familiar with the illness (28, 29). For these participants this was evidenced where it was believed that they have contagious diseases attached to their particular condition. Veterans may not disclose the disease to avoid being watched and judged (stigmatized) by others as sick persons (30). Stigma is a powerful social construct and stigmatization is a process of attaching negative social meaning to an individual or group’s characteristics that is usually associated with chronic disease (31). Stress and worry about stigmatization occurs in social situations as people try to deal with the strain that the stigma places on interpersonal relationships (29). Ultimately individuals may decide to not disclose their condition and to not be in some social situations thereby avoiding the possibility of being stigmatized (29, 32).

In our study another reason for not revealing illness has religious roots. ‘Disability has distinct meanings across cultures and ideologies. ‘It has been understood as a rather general form of punishment or gift from Gods or spirits’ (33, p. 751). The veterans view their participation in the war as a religious and national obligation. In spite of the disease, they were satisfied they acted according to their beliefs and that their illness is a test from God, wherein disclosing it may be ostentatious and diminish its value. These findings are consistent with Taleghani’s study where most participants believed that they ought to pass God’s test in relation to coping with breast cancer (34).

Veterans wanted to be treated like others, as a whole person and not as sick, particularly in social situations. To not be seen as whole disrupts interaction with others in a social situation. Participants stressed the importance of being acknowledged as whole and unique, not being regarded in a different manner from their peers (35). Besides stigmatization, SM poisoning complications are chronic and progressive with exacerbations and disease manifestations that may not be obvious. People may perceive war veterans to be in good health, therefore not seeing and treating them as victims. In everyday life, individuals affected with chronic illness are at risk of being misunderstood especially when the illness is invisible and there are not external signs (24, 36, 37).

Having knowledge of the disease and medical treatment effects is a significant factor in accepting and managing chronic illness consequences (38). Restricted lives commence with inadequate information and treatment. High turnover and healthcare workers’ lack of time results in limited reciprocal communication with clients (39). Consistent with Mali’s study, our results show that for some participants not having adequate information about the disease contributes to restricted social participation (40). Nowadays, client’s active role in regard to chronic illness is emphasized (41). Requisite to healthcare workers providing educational support are teaching and communication skills and an understanding of what it means to live with chronic illness (42). Lack of time and stable relationships, emphasizing objective data and disregarding the subjective narratives, not sharing knowledge with the clients, and not trying to understand persons as a whole is troublesome in healthcare worker and client interactions (43, 44).

Long-term poisoning complications affect victims’ relationships and aspects of life that are often taken for granted, such as where they go and what they eat. Limited physical activity, complex regimens, prolonged hospitalization, not having enough time and energy associated with chronic illness result in relationship loss (42, 45, 46). Not to be an integral part of a social network increases the risk of disability (47). Participants in this study expressed frustration about the unpredictability of living with a chronic disease and the difficulty associated with forward planning that result in further restriction on and disruption to their relationships. The unpredictable course of most chronic illnesses fosters uncertainty so that clients are unable to plan social activities; the result is limited social engagement and avoidance of activity (37, 48, 49). The limitation may disrupt family relationship (37, 45, 49). In our study one participant considered the disease as a contributory factor to his divorce, which was extremely distressing for him. Deep engagement with the illness may result in a person’s ignorance of disease tensions on the family (28), notwithstanding that in this current study, our participants did suffer due to the strains of the disease on their families.

Physical effects of gas poisoning are described as so severe and debilitating that they are associated with a limited capacity to work (15). Physical disability interferes
a lot with participants’ ability to function, especially as they lose their ability progressively. Most participants pinpointed the time when they definitely are not able to walk even 50 m without shortness of breath. Disability arising from the disease that prevents participation in usual daily activities constitutes a significant loss in their life. Participants cannot do their job as well as they could before and as a result, they are unable to fulfil their designated family, work, and community roles. Clients with chronic illness experience problems doing the roles of parent, partner and employee and require stopping or reducing employment obligations (37).

As stated by Chiu et al. (50, p. 19) ‘functional disability refers to an individual’s inability to perform activities in normal daily life, and may be a result of multiple factors interacting over many years such as chronic disease that can be one of the factors leading to functional disability’. Development of a chronic illness is often expected to result in a functional disability that causes dependency on others (33) and the need for formal and informal care (51). Over time as the disease progresses, the participants become more dependent and develop feelings of shame and uselessness, that are in line with the loss of independence experienced as frustration, sadness, ashamed, feelings of being a burden and no longer needed that have been evidence by other studies of chronically ill clients (48, 49, 52).

Furthermore, participants described dependency on special facilities to increase social participation. Despite the work of Martyrs and Veterans Affairs to provide assistance in the social aspects of the lives of victims of chemical warfare, trying to meet the needs of more than 100,000+ war veterans in Iran, makes this task difficult. Chronically ill people are the largest group of health care consumers and have substantially greater health problems than other people (53). In addition, the health system is not sufficiently equipped to meet their needs because of access problems and high costs of facilities (54).

Conclusion

Physical restrictions experienced by war veterans following SM poisoning decrease their functional capacity and levels of independence. In addition, chemical warfare victims are at risk of social interaction disturbance due to stigmatization, misunderstanding, lack of information and facilities. Stigma in the work place as well as poisoning complications and nonpredictability of the disease decreases employment opportunities and relationships. Poisoning complications are sometimes invisible and casualties may be viewed as healthy people not experiencing any health problems. The support provided for chemical warfare victims is appreciated, but the need for more information sharing and more facilities emerges from our data. Lack of information about the chemical warfare poisoning and a failure to understand what it means to live with SM poisoning increases the risk of misunderstanding and stigmatisation. These factors impede interactions and reciprocal communication and so relationship loss occurs. Veterans should be seen as whole individuals as they are not just sick persons who only need medical treatment. If they are perceived just as sick they are not interested to appear in society. They have been champions of society and their different needs should be regarded as important. SM poisoning is a chronic disease, occurring and deteriorating every day so the casualties need more support in passage of time. Family is a source of support for participants and they have to be concerned with their family together. If healthcare professionals and other people who handle poison victims have a better understanding of the victims’ disabilities, it could potentially enable them to be provided more effectively with the facilities they need.

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Author contributions

Hadi Hassankhani conducted the preliminary design, data collection, analysis and drafting of the manuscript. Fariba Taleghani, Jane Mills, Melanie Birks, Karen Francis and Fazlolah Ahmadi were responsible for critical revisions of the manuscript, for important intellectual content and supervision and gave the final design and the final shape of the manuscript.

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