



Disaster and Multiple Sclerosis: A Systematic Review

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Abstract

Background: Multiple Sclerosis (MS) patients experience a variety of disease caused disabilities that makes them more vulnerable to the effects of disasters. This study aimed to review all existed studies about disasters and related disaster management planning about MS patients.

Methods: The PubMed, Google Scholar, Scopus, and Web of Science, ProQuest, science direct, and grey literature databases were searched up to the mid of 2021. All obtained titles were assessed by the inclusion criteria. Abstracts of the relevant titles were reviewed and eligible articles/documents were included for full text review and data abstraction.

Results: From 24616 Articles/documents, finally 15 documents (13 articles, and 2 books) were selected. In 8 articles (53%) specifically, focused on MS patients and, in the rest focused on them as a member of people with disabilities. Most studies (10, 71.4%), emphasized on the disaster induced stress effect on MS patients. In two books/book sections, the disaster preparedness plan for all types of disabilities was presented in general, and MS patients were mentioned as a member of the group of patients with disabilities.

Conclusion: Despite the importance of planning in response to disasters to address specific problems of MS patients, there is a lack of proper planning. This is very important and there is an urgent need to develop appropriate planning protocols for addressing the special conditions of MS patients in response to disasters.

Keywords: Disasters; Multiple sclerosis; Vulnerable populations; Disabled persons

Introduction

The human or natural origin disasters occurring over a short or long period can seriously disrupt the functioning of a community and causes extensive human, economic or environmental loss

in which the affected community or society cannot cope using its own resources (1). All kinds of disasters, both natural and human-made, have various effects on humans, and people with cer-



tain conditions and diseases are more likely to be affected (2).

Multiple sclerosis (MS) is one of the main causes of non-traumatic disabling disease in adults almost in the youth with serious socioeconomic effects (3). MS patients have a variety of disabilities that make them vulnerable to disasters. Part of these vulnerabilities is similar to the general population, and others depends on the complications of the MS (4).

MS maybe cause many sensory or motor disturbances resulted in some degree of disabilities with increase patients' risks in confronting disasters (5). Disability is a complex, dynamic, and multidimensional entity (6), which involved persons face more difficulties and less chance in accessing

community services and assets (7). Due to disability driven declining income, MS patients due to their economic status, like other people with disabilities, are more likely to live in high-risk areas during a disaster. (8).

Disability in MS, derived from attacks that partially or completely destroy nerve fibers almost in the central nervous system. The emerged dysfunctions maybe resolve by passing time in partially destroyed nerves or remain permanently in completely destroyed one (9). These sequels are very different and vary from fatigue to sexual dysfunction (10). There are a significant number of these problems (80% to 90%) simultaneously or alone in MS patients (11) (Table 1).

Table 1: Common problems in MS patients due to disease entity (4)

<i>General</i>	<i>Gastroenterological</i>
<ul style="list-style-type: none"> • Fatigue • Pain 	<ul style="list-style-type: none"> • Swallowing difficulties • Constipation • Urgency or incontinence
Visual and Communication	Higher functions
<ul style="list-style-type: none"> • Visual problems • Speech difficulties • Hearing problems 	<ul style="list-style-type: none"> • Cognitive losses • Emotionalism • Depression • Anxiety
Motor problems	Sexual dysfunction
<ul style="list-style-type: none"> • Weakness/paralysis • Spasticity and spasms • Ataxia and tremor • Pressure ulcers 	<ul style="list-style-type: none"> • Male sexual dysfunction • Female sexual dysfunction
Urologic problems	Other considerations
<ul style="list-style-type: none"> • Bladder symptoms • Urgency or urge incontinence or urinary retention 	<ul style="list-style-type: none"> • Infections

More than 15% of people with disabilities live in the world in which significant proportion of them are MS patients (12). Comprehensive and contingency planning and interventions based on the social model of disability and the structural approach to disaster management help to address disability-driven vulnerability of MS patients (10). There are 2.8 million people living with MS worldwide that significant percent of them have disabilities (11). Disasters generally affect deprived people disproportionately, including disabled people or health problems with chronic

course such as MS (13). As an example, Europe and the USA reported the different impacts of the COVID-19 pandemic as a natural disaster on people with MS (14). Appropriate disaster management planning will be possible by considering all type of problems (Table 1) of MS patients, through a variety of scientific studies (15). Studies on MS and disaster with any related topic is scarce to answer all questions. There are systematic reviews related to disaster and disability, or chronic non-communicable diseases in which in numbers of them, MS patients with disabilities

are mentioned. Because a significant proportion of MS patients are currently being treated for their disease and not having a disability using medication, they are being ignored with this approach, while requiring special attention for disaster management programs (16-19).

With regard to the importance of proper disaster risk management and its role in addressing the multiple needs of MS patients, there are many questions. How many studies currently exist to address specifically MS patients in the disaster management framework? What are the characteristics of these studies related to the all phases of disaster management cycle (Prevention/Mitigation, Preparedness, Response, and Recovery)? The aim of this systematic review was to find the answers to these questions. Examining the existing articles, documents, and their thematic relationship with the pre, in and post disaster phases can reveal the shortcomings in the current evidences. In addition, the results of the present study will help to plan for disaster mitigation and increase patients preparedness for appropriate response at the time of disaster occurrence and in the recovery phase, and identify future necessary studies to full fill gaps.

Methods

We developed a review manual and reported the process of our review and results according to the PRISMA guideline. PRISMA primarily focuses on the reporting of reviews evaluating the effects of interventions. However, it can also be used as a basis for reporting systematic reviews with objectives other than evaluating interventions (20).

Research questions

1. What are the characteristics of the articles on the MS and disasters in terms of article type, study approach (qualitative or quantitative), study setting, results, hazard type, date, and country or affiliation of first/corresponding authors?
2. What are the effects of hazards/disasters on MS patients?
3. Which part of the disaster management cycle does the present study relate to?

3. Is there any kind of planning currently exist for MS patients in disasters?

Definitions

- "Disaster": is "a man-made or natural event that disrupts the affected community functions and results in widespread losses that are greater than community resources" (21).
- "Multiple sclerosis" (MS): is a chronic disease of the central nervous system (CNS) characterized by loss of motor and sensory function that results from immune-mediated inflammation, demyelination, and subsequent axonal damage (22).

Inclusion criteria

- Articles published in peer-reviewed journals and had addressed multiple sclerosis in the context of disasters.
- Articles in any format including editorials, case reports, reviews, and original research.
- Books or Guidelines had addressed Multiple Sclerosis in the context of disasters.

Exclusion criteria

- All non-English articles, unless an English abstract was available.
- Papers with abstracts that did not include enough information or were not accessible for extraction of the study variables.

Search strategy (Data sources and literature search)

We searched 6 databases, including PubMed, Scopus, Google Scholar, and Web of science, Science Direct and ProQuest. We searched the databases for retrieving published articles up to the mid of 2021. In addition, grey literature was searched through the "New York academy of medicine grey literature reports" (23). Websites of MSIF, WHO, UNDRR, and PreventionWeb searched for relevant guidelines. We also reviewed the references of retrieved studies to identify additional articles.

We chose key terms and developed a search strategy based on the National Library of Medicine "Medical Subjects Headings (MeSH)".

The following search strategy was applied in the PubMed database: “(disaster [Title/Abstract]) AND Multiple Sclerosis [Title/Abstract]”.

For searching in the other databases, we did it similar to the PubMed search strategy. Searched contents were limited to titles and abstracts of articles.

Study screening process

Primarily, with the mentioned keywords we searched databases limited to abstracts and titles. The results were reviewed by members of the review team (RH, YST, and FG). If there was any uncertainty for meeting the inclusion criteria, a decision was made based on consensus. After excluding unrelated articles, the remaining were evaluated to exclude duplicates. Then, the abstracts of the selected titles were screened to reach the final list.

Data analysis and quality assessment

The finally included papers were evaluated by members of the research team (TA, SMB, HC) using a data abstraction sheet developed by the research team. This data sheet included the study variables: Author, Title, Publication Type, Study type, Hazard/Place in DM cycle, Study population, Disability, Results, limitations, Year, Country. The final selected articles were examined for quality assessment by using of strengthening the reporting of observational studies in epidemiology (STROBE) checklist with the score ranging from 0 to 34 (24). In this review, studies were classified into 3 groups according to their obtained score as weak quality, ranging from 0 to 12; moderate quality, ranging from 13 to 23; and high quality, ranging from 24 to 34.

Ethics approval

This study approved by the Human Research Ethics Committee (Confirmation number: IR.MAZUMS.REC.1398.1050 date: 16.10.2019).

Results

Literature search

The initial search resulted in 24616 articles/documents (24589 resulted from database searching and 27 documents resulted from Grey literature and website searching). After removing duplicates, 21481 titles did not fulfill the inclusion criteria and they were excluded. The abstracts of remaining 132 articles/documents were examined in which 81 irrelevant abstracts and four articles without full texts (their abstracts were not informative enough) were excluded and 42 articles/documents were considered for full-text review. In total, 13 papers and 2 books/series were included in the final review list for data extraction. Figure 1 outlines the literature search and the study selection process.

The affiliations of the first/corresponding authors of articles were the USA (n=9, 60%), Israel (n=1, 6.7%), United Kingdom (UK) (n=1, 6.7%), Iran (n=1, 6.7%), Lebanon (n=1, 6.7%), Australia (n=1, 6.7%), and Japan (n=1, 6.7%). The 13 papers were published in 10 different peer reviewed journals.

The earliest document was published in 1989 and the last document were published in 2021. There was an increase in the number of published documents of MS-related to disaster from 2008. For example, in 2009, 3 documents, and in 2010, 2 documents were published. Fifteen studies focused on 7 hazards types including all hazards (n=5, 33.3%), man-made (war) hazards (n=4, 26.7%), earthquake (n=3, 20%), natural hazards (n=1, 6.7%), complex humanitarian emergencies (n=1, 6.7%), fire and epidemic (n=1, 6.7%), and the book mentioned all hazards. The 4 studies were review articles (26.7%) and remain where any type of observational studies (cross-sectional or cohort).

Quality assessment of studies

Based on the quality assessment 5 studies were categorized as weak, 6 studies categorized as moderate, and 4 studies were categorized as high level of quality.

Results of included studies

Fourteen documents (Table 2) finally selected for review were divided into 2 groups according to

the population of the study (4, 5, 19, 25-35). In 8 articles (53.3%) specifically, focused on MS patients as study population and, in the rest focused on them as a member of people with disabilities. Only in 6 (40%) documents, the type of disability of the study group was discussed, 4 (26.7%) of which were about all types of disabilities, and the

rest 2 (13.3%) documents were about motor disabilities. Just in two books/book sections, the disaster preparedness plan for all types of disabilities has been presented in general, and MS patients were mentioned as a member of the group of patients with disabilities.

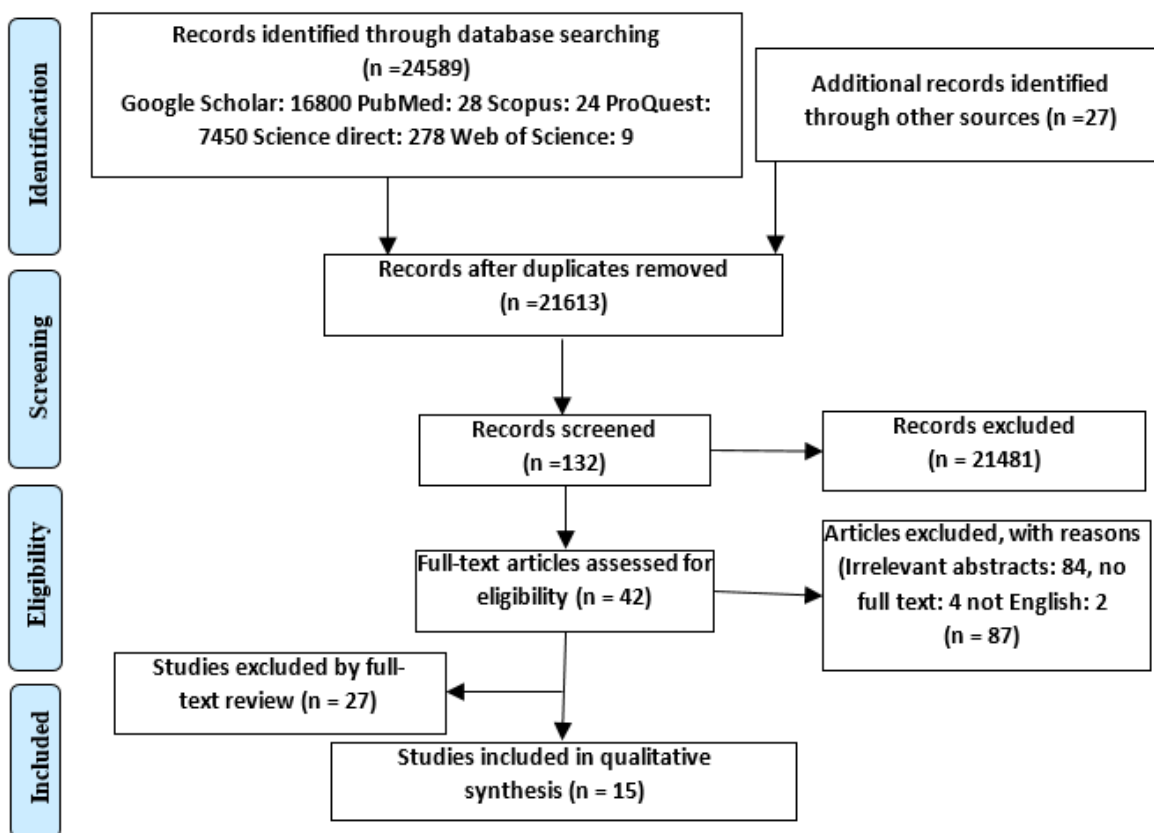


Fig. 1: Flow diagram of the articles selecting process

In 10 (66.7%) studies, hazard exposure was a risk factor to increase relapse rate or the emergence of MS, and just one study did not find any correlation. A history of exposure to stressful events, especially in the last 6 months, is a factor in the occurrence or recurrence of MS attacks. Disabled patients had significantly more problems dealing with disaster-induced limitations like mobility problems or access to resources that mentioned in 3(20%) articles. One document (6.7%) has

been presented guidelines on disaster preparedness plans for MS patients as a member of the disabled population.

There were many limitations in studies. Memory problems to recall past experiences in the retrospective questionnaire-based studies, the small scale of the study population, and lack of evidence-based knowledge, limited empirical and evidence in the area of mental health, and simulated study area, were samples of these limitations

Table 2: The reviewed articles characteristics

<i>Author</i>	<i>Title</i>	<i>Publi- cation Type</i>	<i>Study type</i>	<i>Haz- ard/Plac e in DM cycle</i>	<i>Study popula- tion</i>	<i>Disa- bility</i>	<i>Results</i>	<i>limitations</i>	<i>Ye ar</i>	<i>Coun try</i>
Grant, Igor et al.	Severely threatening events and marked life difficulties preceding onset or exacerbation of multiple sclerosis	Journal article	Case control retro- spective cohort	All haz- ards / Mitigation	39 pa- tients and 40 matched Non- patient volun- teers.	NR	Almost three quarters of new MS pa- tients experi- enced a marked adversity in the 6 months prior to onset of disease.	Temporal relationship cannot prove causal effect	19 89	UK
Rahimi, Mansour	An examina- tion of be- havior and hazards faced by physically disabled people dur- ing the Lo- ma Prieta earthquake	Journal article	Cross- Section- al, de- scriptive	Earth- quake / Mitigation and Prepared- ness	Physical- ly disa- bled persons including MS pa- tients	Severe to Moder- ate physical disabil- ity of upper and lower limb	-No sig- nificant differ- ence between degree of disability and haz- ard ex- posure. - Con- trolled behavior for ap- propriate actions with prior training	-No statisti- cal random- ization -limited included category of Physical disability -No com- parison between groups -Specific building contents not consid- ered -Rely on memory recall after 3 months -Small sam- ple size	19 93	USA
Rahimi, Mansour	Behavior of mobility- disabled people in earthquakes: A simulation experiment	Journal article	Case- control by static simula- tion	Earth- quake / Prepared- ness	Mobility disabled persons including MS pa- tients	Disa- bled patients use wheel- chair and motor wheel- chair	Disabled patients had sig- nificantly more problem to deal with damage of low and high intensity	Not real earthquake environ- ment with using simu- lation video streaming	19 94	USA

Wallin, Mitchell T et al.	Multiple sclerosis in US veterans of the Vietnam era and later military service: race, sex, and geography	Journal article	Retrospective cohort	Manmade (War) / Mitigation	US veterans of the Vietnam	NR	earthquake Increased risk for developing MS, significantly	NR	2004	USA
Golan, Daniel et al.	Impact of exposure to war stress on exacerbations of multiple sclerosis	Journal article	Retrospective cohort	Manmade (War) / Mitigation	156 MS patients	NR	Increased risk for MS relapse	Just focused on clinical assessment of the impact of stress war on the disease activity	2008	Israel
Mohr, David C Pelletier, Daniel	A temporal framework for understanding the effects of stressful life events on inflammation in patients with multiple sclerosis	Journal article	Review article	All Hazards / Mitigation	MS patients	NR	Stressful life events is related with MS exacerbation	NR	2006	USA
Barth, Shannon K et al.	Neurological Mortality Among U.S. Veterans of the Persian Gulf War: 13-Year Follow-Up	Journal article	Prospective cohort	Manmade (War) / Mitigation	621,902 veterans of Persian Gulf War (GW), and 746,248 non-GW veterans.	NR	There was no excess of MS deaths	- potential selection bias - No information about behavioral and occupational risk factors	2009	USA
Davis, Elizabeth Phillips, Brenda	Effective Emergency Management: Making Improvements for Communities and People with Disabilities	Book	NR	All hazard / Mitigation, Preparedness and, Response	People with disability including MS patients	All type of disabilities	Outline protocols for emergency managers	Lack of evidence-based knowledge	2009	USA
Stough, Laura	The effects of disaster on the mental health of	Book section	NR	All hazards / Mitigation,	People with disability including	All type of disabilities	Problem for disabled people	Limited empirical and evidence in	2009	USA

	individuals with disabilities			Preparedness	MS patients		especially severe mental illness to access resources before, in and after disaster	this area of study			
Mateen, F. J.	Neurological disorders in complex humanitarian emergencies and natural disasters	Journal article	Review article	Complex Humanitarian Emergencies and Natural Disasters / Mitigation	People with Neurological Disorders including MS Patients	All neurological disability included	Stress induced relapse rate of MS and long term effects of disasters	NR	20 10	USA	
Yamout, Bassem et al.	The effect of war stress on multiple sclerosis exacerbations and radiological disease activity	Journal article	Retrospective	Manmade (War) / Mitigation	A group of 216 patients with clinically definite relapsing remitting MS	NR	Both clinical and radiological evidence of increased MS disease activity	Lack of objective measures of war-related stress.	20 10	Lebanon	
HabibiSaravi, Reza et al.	Multiple Sclerosis and Disaster. On occasion of the International Day for Disaster Reduction in 2013: disability and disaster, at ACTRIMS Forum 2016	Conference article	Review article	All hazards / Mitigation,	Multiple sclerosis patients as member of disabled person	All neurological disability included	Any type of disaster has short and long consequences or direct and indirect effects on MS patients	All documents full text not accessible	20 16	Iran	
Kuwabara, S. et al.	Neuroimmunology of a natural disaster	Editorial commentary	Narrative review	Natural / Mitigation	MS patients	NR	Psychological and physical stress influences the activity of autoimmune diseases including multiple sclerosis	NR	20 17	USA	

Kanamori, Y. et al.	Impact of the Great East Japan Earthquake in 2011 on MS and NMOSD: a study in Sendai, Japan	Letter to editor	Cross-Sectional, descriptive	Earthquake / Mitigation	203 patients (140 with MS and 63 other)	NR	The earthquake caused significant stress in patients with MS and NMOSD, but did not observe a significantly increased relapse rate or higher disability.	Recall bias can occur in the questionnaire-based evaluation of stress. Small scale of study population	20 17	Japan
C. H. Marck, et al.	The effect of the Australian bushfires and the COVID-19 pandemic on health behaviors in people with multiple sclerosis	Journal article	Cross sectional Descriptive	Fire and Epidemic / Mitigation	People living in Australia with a diagnosis of MS, and MS community members (MS healthcare professionals, carers, and advocates)	NR	Significant changes to health behaviors in people with MS as a result of the Australian Black Summer bushfires and the COVID-19 pandemic.	1-Small sample 2- Non-English speakers, without access or inability to use the internet were not included. 3-Severe levels of disability may be underrepresented. 4- Data did not include socio-economic, social supports, or other social determinants of health measures 4- Results are cross-sectional, and changes in health behaviors	20 21	Australia

may have
fluctuated
throughout
the crises
5- Need
more im-
portant data

NR=Non reported

Discussion

The main aim of the study was to identify the existing plans and their characteristics to address all needs of MS patients in disaster management. PubMed searching for the term “disaster” gave us more than 101,086 papers, but we could only find 13 papers and 2 books about MS and disaster. The first article related to the disaster was published in 1880 whereas, the first article related to the MS and disaster was published in 1989. There was a 109-years gap between the 2 publications. The reason for this time lag is due to the unknown nature of MS until the last few decades (36). Therefore, MS in the field of disaster is a pristine research area, although there has been a growing interest in this area in recent years after 2008.

In recent decades, many countries have spent millions of dollars on improving their emergency management systems in the face of disasters (37). Consequently, the comprehensive response to disasters has become a focus of the investigations to ensure that resources are used more efficiently and all affected populations, including MS patients, as a member of the vulnerable population, have appropriate access to the resources (18). The Sendai Framework for Disaster Risk Reduction 2015-2030 also emphasized the importance of comprehensive planning for people with disabilities (38).

Multiple sclerosis patients have many types of disabilities and are members of vulnerable groups in disaster (34). Hence, comprehensive disaster management planning must address different needs of all types of disabilities in MS patients even with minor disabilities or serious problems.

Mitigation/Prevention/Preparedness: Due to the variety of complications of MS patients, many vulnerabilities can be expected that should be proportionally analyzed with a comprehensive risk assessment to eliminate the risks or reduce the effects of disasters on them.

The vulnerability of MS patients with physical disabilities in the face of earthquakes was investigated. In these studies, patients due to the movement limitations had a higher vulnerability compared to the control group in structural damages and no significant difference was observed in non-structural damages. In the event of an earthquake, these patients need appropriate measures to facilitate exits access from the building, as well as to provide appropriate tools and facilities in order to respond appropriately (26, 27, 39).

In several subsequent studies, various aspects of vulnerability of patients with mobility limitations in the face of disasters were analyzed. Operational guidelines were provided to implement corrective measures in building structures and improve the placement of non-structural components. These plans are available for MS patients with physical disabilities similar to other people with disabilities (19, 40-42). Actually, for other complications of MS, appropriate plans should be made available to patients, while they are usually presented in a general format and may not even mention MS patients (42).

Disaster risk assessments for chronic non-communicable diseases, including multiple sclerosis that require ongoing medication and medical care, revealed that exacerbation of the disease is expected due to impaired access to these facilities. For this reason, the necessary planning and preparedness in the face of disasters by both patients and related organizations is essential (7, 43, 44).

Response/Recovery: In most studies, core research orientation was focused on the effect of disaster-derived stress on MS emergence or relapse in the short or long term. Although in early studies, the cause of this relationship was not clearly found, in several subsequent studies, the relationship between the incidence or exacerbation of MS and stress caused by disasters, especially man-made disasters such as war and conflict, were emphasized (29, 30, 45-50). This effect was particularly evident at intervals of less than 6 months after disasters (25, 46). In a few studies that did not find a clear relationship, the length of the study period, small sample size or bias in sampling can be considered as the causes (25, 35). Stress inflicted on human society due to disasters in various studies related to different hazards as a risk factor in the occurrence or exacerbation of various diseases, especially chronic and non-communicable diseases such as psychological disorders (PTSD, depression, etc.), hypertension and diabetes has been revealed (51, 52). These findings emphasize the importance of psychological support in disasters and preventive interventions to reduce the perceived stress of disasters (53).

Because of the disability diversity of MS patients, there is a need for comprehensive contingency planning to address all of their special needs at the disaster. Due to the chronic nature of MS and the new promising treatments that control its progression, the cumulative number of MS patients will increase in the upcoming years (54). In this regard, MS patients' data should be included in geospatial information systems (GIS) which guide the coordination of emergency response, and the development of frameworks for understanding the functional needs of MS patients especially those with disability, in communication, mobility, transportation, and their medical needs (53).

Another important issue that comes from disability perspective in MS patients is any kind of abuse. Risk factors for abuse in MS categorized into three groups by specialists; frustration, lack of communication and the feeling of having no place to turn. Insecurity is inevitable disaster con-

sequence (4). The greater the scope and intensity of disasters occurred, the more impact it will be on insecurity. In these circumstances, the MS patients according to level of physical or mental disability would have more vulnerability and less defense against violence. This can lead to a worsening of damage and consequences of disaster that was mentioned earlier (54). This concern should also be addressed in the MS patients' disaster Response plan.

Limitations

This review has some limitations. Studies were only included if the texts or abstracts were available in English. Therefore, there is a bias in the selection of studies. However, high sensitivity was used in the database search, yielding more than 24616 titles.

Conclusion

Disabled people, specifically MS patients, are amongst the most vulnerable part within the general population. They must receive continuous support to prepare for disasters. While majority of studies included in our review presented some evidence for the effects of disaster on MS patients specially stress effect, research is needed to address contributing factors, and means of managing disease in the extremely resource-scarce disaster settings. There are few studies about MS and disasters and there is no dedicated disaster management program for MS patients. We need more studies on different aspects of MS, as vulnerable populations, and disasters and the need for comprehensive disaster preparedness/response/recovery planning for MS patients. It is needed to address all types of disabilities/problems and design an appropriate framework of disaster management to cover the different needs of MS patients. In this regard, utilization of registered information resources of Electronic Health Records (EHR) as well as the use of information registered in the Geographic Information System (GIS) in the event of disasters

facilitates to meet the needs of MS patients by knowing their right number, needs and location. The increasing trend in the number of MS patients around the world emphasizes the importance of comprehensive disaster management planning for them. Therefore, it is necessary to conduct further studies in assessing vulnerabilities, structural or non-structural improvements in the building, access routes, and response as well as disaster recovery plans to achieve these aims.

Journalism Ethics considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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Conflict of interest

The authors declare that there is no conflict of interests.

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