Original Article

# Comparative study on National Burn Registry in America, England, Australia and Iran

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## ABSTRACT

Context: Iran experiences a high rate of burns accompanied by painful consequences, death and a lot of disabilities. In order to reduce the burden of this injury, some strategies such as designing and implementation of registration systems are essential. Aims: The aim of this study was to compare National Burn Registry in America, England, Australia and Iran. Materials and Methods: This study was comparative-descriptive in which data collected from the National Burn Registry of America, England, Australia and Iran studied in 2013. The study population included National Burn Registry of these countries and data was collected using raw data forms. Statistical Analysis Used: Data on each country was categorized according to objectives and comparisons took place using comparative tables. Finally, descriptive-theoretical analysis of the findings was performed. Results: National Security Agency and National Burn Repository in America, National Institute of Health and the Ministry of Health in England and the Department of Health and Senior in Australia are responsible for national burning registry. A seven-axial model was proposed for Iran's National Registry. America's registry system is broader than other countries due to its cooperation with Canada, Sweden and Asia. **Conclusion:** The aim of the Burn Registry System is to gather, store, edit, categorize, analyze and distribute all burns, injured data from all health care centers in a specific population and provide valuable information about the occurrence, time and regional distribution of burn injury.

Key words: Burn, information management system, information registry system

#### INTRODUCTION

A burn is a kind of skin or mucous membrane injury due to excessive heat or cold, chemicals, electricity and radiation.<sup>[1]</sup>

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It is the leading cause of morbidity and mortality in the world with serious economic and social consequences. It also constitutes about 5-12% of world's trauma<sup>[2]</sup> and is considered among those events which affect a lot of people every year. Pains and related side-effects of it may continue for a long time and have long-term impacts on individuals, families and communities.<sup>[3-5]</sup>

Burn is the fourth cause of mortality after vehicle accidents, fall from a height and violence. During a study which was performed in Turkey, 63% of household events are associated with burn. This event is related to a high percentage (%63) of accidents causing death, disability, pain, physical, psychological and economic problems and paralysis.<sup>[6]</sup> In a study in Mashhad, the mortality rate was %25.9 which was lower compared to Shiraz (%34.4), Tehran (%43.9), Kuwait (%28.4), Pakistan (%62), Turkey (%33.5), Sri Lanka (%27) and above 60 years of age in France (%39). However, it was higher than

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Saudi Arabia (%7.4), Afghanistan (%16), Holland (0.5 in 100000), Portugal (%3.7) and India (%19.7). High mortality rates can be attributed to high levels of infection and septicemia, *Pseudomonas*, resistant to many anti-microbial agents, unavailability of selective antibiotics due to patients' unfavorable economic conditions, lack of medical and health care facilities, ineffective care and treatment.<sup>[7]</sup> On the other hand, the type, extent and causes of burn are different all over the world due to different lifestyles. Investigations show that life-style, social, economic and cultural level along with energy sources at home and work can change the extent and type of burns.<sup>[8]</sup>

The process of injury, treatment and rehabilitation of burn has both physical and psychological impacts on victims. Unfavorable prognosis due to scar, deformity and limitation of movement leads to a different future and brings about numerous economic problems for injured people.<sup>[9]</sup> In the meantime, Iran is experiencing a high rate of burns with painful consequences, deaths and disabilities. However, it is obvious that sufficient data such as type, extent and causes of burn on victims will be helpful in finding proper and cost-effective strategies to deal with these problems. Type, extent and causes of burn are different regarding various life-styles in different parts of the world. According to investigations some factors such as life-style, social, economic and cultural level and energy used at work or home can change the extent and type of burns.<sup>[10]</sup>

The key element in control and improvement of every disease is correct and sufficient data on patients, manner, time and place of the occurrence of disease. In modern medicine a lot of data is produced, but there is a deep gap between data collection and interpretation.<sup>[11]</sup>

The information management system is a professional system which collects, interprets, summarizes, restores and reports data. Therefore, data collection is the first and most important part of information management that provides data to be stored in databases and confirms its reliability for future use. The information management system provides data through a basic understanding of data concept: Where it comes from, what kind of data is collected, ad why it is needed. Therefore, the data should be organized in such a way that it can be restored, because all available data is broad and confusing.<sup>[12]</sup>

Therefore, it seems necessary to have a database in order to collect, process and distribute data. In other words, the information management related to processes or consequences of a disease is essential, because it makes the comparisons possible. Obviously, in order to compare data, information about each individual should be collected according to the same procedures.<sup>[13]</sup> Thus, each country needs to establish such a system according to its objectives, rules, national requirements and standards.<sup>[14]</sup>

Until now, some attempts have been made to provide a registry system for acute coronary syndrome, diabetes, cancer, trauma, mental health, transplant and mortality in Iran;.<sup>[11,15-20]</sup> However, there is no consistent study on the design and implementation of minimum data set (MDS), registry system or information system based on international burn standards.

This information is essential to design preventive and decreasing programs for the consequences and mortality of burns, identifying patients' prognosis, adopting appropriate strategies in order to prevent burns which play the most important role in bringing about unfavorable consequences, decrease costs, mobilize burn centers and return victims to work and society as soon as possible.<sup>[21]</sup> Registry system is a set of secondary data on patients with a particular diagnosis, condition, or action. Registry systems often require extensive data entry for patients' records. The fundamental objective of registry systems is collecting data from health records and making it available to the users.<sup>[22]</sup> Abdelhak et al. believethat registry systems provide some activities such as tracking patients' referral patterns, evaluating follow up process and quality of patient care, creating essential data for administrative planning and valuable sources of health care system and finally, providing medical marketing programs.<sup>[23]</sup> Designing and implementing registry systems can be effective in data collection, process and distribution in the form of information which is related to processes or consequences of disease.<sup>[11]</sup> Some strategies such as design and implementation of registry systems are essential in order to reduce the burden of this disease.<sup>[24]</sup> Currently, there is no efficient national burn registry in Iran to meet the requirements of this section; therefore, the aim of this research was to compare burn registry systems in America, England, Australia and Iran.

## MATERIALS AND METHODS

This study was comparative-descriptive in which National Burn Registry of America, England, Australia and Iran studied in 2013. Study population included National Burn Registry of these countries and data was collected using raw data forms. Data collection methods included observations, studies and interviews. Data sources included articles, books, journals, databases, related websites, E-mails, other written documents, data registry centers through databases of researchers and experts in the burn registry system. Data was collected using raw data forms, its reliability was confirmed through a group of experts in health information management and surgeons from all over the country. Data on each country was categorized according to objectives and comparisons took place using comparative tables. Finally, descriptive-theoretical analysis of the findings was performed.

#### **RESULTS AND DISCUSSION**

The first category compared in America, England and Australia was the objective of national burn registry system. According to the findings, the main objective of this system is providing strategies to prevent burns, provide sufficient knowledge to improve patients' treatment and quality of life and rehabilitation after burn.<sup>[25-27]</sup> However, Iran doesn't have such a system and there are no specific objectives in this case [Tables 1 and 2].

In order to determine the structure of the national registry system in America, England and Australia, some specific criteria were used, including: Responsible organization for data collection, location of the responsible organization, committee members of the responsible organization, type of the registry system, registration centers and methods of organizing these centers.

Based on these findings, the emphasis of the burn registry system in selected countries is on preventive and epidemiological researches.  $^{[25\cdot27]}$  Other studies which have been done on registry systems for cancer and diabetes confirmed these results.  $^{[28\cdot30]}$ 

Australia aims to encourage the development of stronger standards in terms of both burn injuries and burn care through education and research. Burn epidemiology description, policy development for the prevention of burn injuries, supervision on the manner and quality of burn care management, creating clinical outcomes for burn patients, service planning improvement and development of best clinical guidelines are other objectives considered in this country.<sup>[27]</sup> In America registry system aims to improve the lives of people who have been affected by the burn, support

Table 1: Objectives of burn registry system in selected countries <sup>[25-27]</sup>						
Australia <sup>[27]</sup>	America <sup>[25]</sup>	England <sup>[26]</sup>	Iran			
Encourage to develop stronger standards in terms of burn injuries and burn care through education and research	Improve the lives of people who have been affected by the burn	Burn prevention	There is no national burn registry system and therefore, there are no specific goals			
Descriptive epidemiology of burn	Support burn-related research and training	Disseminate knowledge for better treatment and rehabilitation of burn				
Develop policies for the prevention of burn injuries	Support patient care, rehabilitation and prevention of burns	Identify common needs of patients at all times				
Monitor the manner and quality of burn care management						
Establish clinical outcomes from burn patients						

Improve service planning Develop best clinical guidelines

Table 2: Structure of national burn registry system in selected countries <sup>[25-27]</sup>							
Comparison criteria		Selected	l countries				
	America <sup>[25]</sup>	England <sup>[26]</sup>	Australia <sup>[27]</sup>	Iran			
Responsible organization for data collection	National Security Agency-National Burn Repository	National Health Organization	Office of Health and Senior	-			
Location of responsible organization	Chicago	Ministry of Health	Australia and New Zealand	There is no National Burn			
		Birmingham		Registry			
Committee members of responsible organization	American Burn Association Multifaceted experimental committee	Committee members were listed by name	Committee members were listed by name	-			
Type of registry system	Computer	Computer	Based on internet	-			
Registration center	American Burn Repository	National Health Organization	National Burn Association	There is no			
			Australia-New Zealand	National Burn Registry			
Methods of organizing registry centers	Decentralized	Decentralized	Decentralized	Registry centers are very limited and there is no relation between their performances			
	Burn Association provides centralized supervision	Burn Association provides centralized supervision	Burn Association provides centralized supervision				
Data collection sources	Trauma patient care centers, hospitals related to trauma and burn centers	National Health Organization	Burn centers that are distributed internationally across Australia and New Zealand	-			

burn-related research and training and also support patient care, rehabilitation and prevention of burns.<sup>[25]</sup> In England, this system aims to prevent burning, disseminate knowledge for treatment and rehabilitation of burn and identify common needs of patients at all times.<sup>[26]</sup> However, Iran doesn't have a specific registry system and no objectives have been established in this respect.

In England, clinical data related to burn injuries are collected from centers which are supervision of the National Health Organization (NHS), hospitals and primary care centers. Data is then recorded under the title of British Isles Burn Injury Database which collects data from different systems. The British NHS has designed software systems for data collection and analysis. In 2004, British National Burn Care Group allocated a budget for creating a national data collection system and supporting its infrastructures. Data collection and analysis started in 2005. This software extracts data for managers, research and epidemiological works.<sup>[26]</sup> In America, data are collected from trauma patient centers, hospitals related to trauma and burn centers. American Burn Association collects and analyses this data. Some regional offices of this Association are in Canada, Sweden and Asia which cooperates simultaneously. American Burn Repository Committee reports annually its performance and aims to support researches related to burns and education while at the same time supports patient care, rehabilitation and prevention of burns.[25] Australia and New Zealand work cooperatively and there are seventeen burn centers in Australia. Burn data is extracted from these centers and those sites that are confirmed by Formal Ethics Committee cooperate with Bi-National Burn Repository (Bi-NBR). Only 12 sites from 17 (%60) act in this area and the budget for burn patients is provided by the public sector (Department of Human Services/University. Data is restored through patients' records and hospital information systems. Next, it is entered into a special national burn registry forms based on web.<sup>[27]</sup> In the Iran data collection is limited to some hospitals and burn centers, which are considered as burn data sources.

The decentralized data registry is used in selected countries under the supervision of Burn Association. In Iran burn registry centers are very limited and there is no relation among their performance.<sup>[25-27]</sup>

InEngland"International Statistical Classification of Diseases and Related Health Problems-10<sup>th</sup> revision (ICD-10)" is used for burn injury coding (to access data faster, easier and compare burn injury in national and international levels). For measures taken, "Office of Population Censuses and Surveys Classification of Interventions and Procedures-4" is used. To code burn records, they also refer to "SNOMED-CT".<sup>[26,31]</sup> In America, burn diseases coding is done according to "ICD-9-Clinical Modification". E-codes section of this book is helpful in coding burns based on depth, extent and causes. To code the measures taken for patients, "Current Procedural Terminology" is used.<sup>[25]</sup> In Australia, codes for diagnosis and international categorization of diseases are extracted from hospital information systems, according to "ICD-10-Australian modification". These codes are then entered into Bi-NBR burn information systems.<sup>[27]</sup> In Iran, coding of burn records is done based on "ICD-9-CM".

#### CONCLUSION

The aim of the Burn Registry System is to gather, store, edit, categorize, analyze and distribute all burns, injured data from all health care centers in a specific population and provide valuable information about the occurrence, time and regional distribution of burn injury, it is one of important and vital requirements for the creation and use of electronic health records in every country. Design and implementation of registration systems are helpful in data collection and analysis; therefore, policy makers should pay special attention to implement of such a system in Iran. It can be concluded from the findings that the design and implementation of a national registry system are not limited to collecting data related to injury but also includes data analysis and distribution.

#### SUGGESTIONS

It is recommended to design and implement a national burn registry system based on the results from comparative studies in other countries and applying them in Iran. In order to improve burn registry system, administrative officials of Health Ministry should consider the following suggestions: (i) Establish national burn registry system in the country; (ii) implement educational programs in order to improve quality of burn information, registration; (iii) use information technology to relate registration systems on line; (iv) establish Burn MDS; (v) develop and reinforce information systems related to burn using information technology. In this system, data should be collected through the same data elements. Moreover, information needs to be distributed among all authorized users after data collection and analysis.

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Ajami and Lamoochi: National burn registry

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