Challenges of Rheumatoid Arthritis Registry in Iran: Qualitative Content Analysis

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Abstract

Objectives: A registry is a vital tool for understanding genetic fields and therapeutic strategies for the treatment of rheumatoid arthritis (RA). In addition, it is valuable in research related to the long-term effect of drugs on patients. Therefore, this study aimed to explain the challenges of RA registry in Iran.

Materials and Methods: Using a purposive sampling method, ten rheumatologists were selected as the samples of the current qualitative research. Further, semi-structured interviews were conducted to the saturation level for collecting the data. Finally, the content analysis was performed to collect and name data, as well as to obtain analytic categories and subcategories.

Results: The challenges were classified into physical (software and hardware), financial (financing), human (skilled personnel for RA data entry and the tendency of more specialists for medical treatment), and managerial (the lack of referral system and support of Ministry of Health) variables, along with time parameter (the lake of time for health and education). The lack of proper infrastructure, financial limitations, and management challenges were among the most important barriers.

Conclusions: The findings showed that RA registry faces many challenges in Iran. In the case of eliminating the existing obstacles, it would be possible to take advantage of effective and useful outcomes in the basic care of patients with RA.

Keywords: Registry, Rheumatoid Arthritis, Content Analysis

Introduction

Rheumatoid arthritis (RA) is one of the most common autoimmune diseases and a chronic and untreatable systemic inflammatory disease which leads to destruction, deformity, or decreased joint function (1-3). The prevalence of this disease, according to the World Health Organization (WHO), was about 1% and it was reported 0.34% in Iran (4). The disease information plays a key role in determining health priorities and each health system requires this information for decision making and planning on health problems and allocating the intended resources at the national level (5).

In addition, large amounts of healthcare data can be accessible and useable through standard and appropriate data collection such as registries (6).

Given that the RA is a chronic and non-treatable illness (2,3), it requires monitoring and lifelong treatment. Therefore, the lack of an RA registry system complicates the creation of real data respecting promoting clinical decision-making for patients while not providing the potential for improving patients' therapeutic outcomes. Further, the absence of such a system has generally adverse effects on achieving high-quality treatment (7).

There are three main types for registries including public health, clinical, and product registries. Public health registries are applied for estimating disease prevalence and trends over time, place, and individuals. Furthermore, clinical registries are specifically useful for investigating disease history and product registries are used for products such as medical equipment and pharmaceutical products (8) Registries require information technology infrastructure development in order to fulfill their goals and to be functional. In Iran, information technology (IT) structure is complex and insufficient to support large IT-based and clinical projects thus there is no responsible body to perfectly support IT-based healthcare projects. Most stakeholders are reluctant to share their responsibilities and thus act as individual islands and therefore, government policy documents are separately designed in such environment while not shared among different beneficiary groups. Moreover, the information and communication technology (ICT) coverage and internet differ across the country and some rural remote areas have no or very limited ICT access, leading to weak E-Health development in the country (9). To develop RA registry in Iran, understanding the existing challenges and

barriers are necessary for helping to describe the current situation and plan based on situational analysis.

Reviewing the available documents in Iranian Rheumatology Informatics Portals and National Programs for Registration of Diseases, there was no document to confirm the presence of national RA registry system (10). Nevertheless, cancer registry has been implemented in the country almost for years and has been used for improving the quality of patients' care and for research. In this regard, the present study sought to investigate the challenges and obstacles in creating a registry system in Iran.

Materials and Methods

This qualitative study used a content analysis approach to evaluate the challenges of establishing an RA registry system in Iran. The interviewees were only selected from among the rheumatologists because RA is a completely clinical issue and the interviewees had already an experience of disease registry.

The participants included ten rheumatologists (60% female and 40% male) in four hospitals affiliated with Tehran Universities of Medical Sciences, who had a work experience of 4-22 years. Similarly, the average age of participants was 42 and the data were collected through semi-structured interviews. The time and place of the interview were determined in agreement with the participants and it was conducted in the department of rheumatology and clinics of educational hospitals. In addition, each interview lasted for 45-90 minutes. Further, the aims and method of the research were explained to all participants so that to observe the ethical considerations.

Likewise, the interviews were started with some proposed questions about the status of RA data registry and then guided by participants' responses. Furthermore, they were recorded by the interviewer upon the participants' consent

The obtained data were then analyzed using Graneheim and Lundman's method (11). They proposed five steps for analyzing the qualitative data as follows.

- Transcribing each interview immediately after its completion;
- Reading the interview text to understand its content;
- Identifying the meaning units and primary codes;
- Classifying similar codes in more comprehensive classes;
- Determining the content contained in the data.

The data collection process continued to data saturation and the failure to obtain new data, followed by employing conventional content analysis approach to analyze the data. Based on the steps in the content analysis process, first, each interview was reviewed several times to get initial and general perceptions and the important points were extracted and then, the meaning units in the interviews were determined accordingly. Next, these units were labeled as condensed meaning units. The coding was conducted using the implied codes and the words which

were expressed by the participants. Eventually, the codes were compared in terms of similarities and differences and were classified into a number of categories and subcategories.

Lincoln and Guba' view was considered to confirm the validity and reliability of data (12). The researcher spent 9 months (October-February, 2018) to collect and analyze the obtained data. This long-term involvement attracted the trust of the participants. After establishing the initial codes, the participants' feedback was taken into account to ensure the validity of the codes and interpretations and correction was conducted in the case of inconsistency. Moreover, two faculty members, who were specialist in qualitative research, controlled the codes to establish the final codes and classification.

Results

The participants, including four males and five females, were within the age range of 40-56 years old and their average work experience in rheumatology was 10 years. In the interview analysis, 13 categories were determined after removing repetitive codes and merging similar cases. Then, comparing and examining similarities and differences, five subcategories were identified including physical, financial, human, management, and time variables (Table 1).

1. Physical

The physical barrier refers to the lack of necessary items to create a proper registry system. This subcategory is divided into hardware and the software categories.

1.1. Hardware: This implies a set of physical hardware which is essential for launching a registry system regarding RA and includes space and equipment and proprietary form subcategories.

Space and equipment: The lack of equipment (e.g., computers, cables, network cards, and the like) and space to deploy equipment for RA registering was reported as a challenge by the interviewees.

(P9): "*We do not have enough physical space to put equipment which is needed for registration such as computers, printers, and the like.*" (A 52-year-old female rheumatologist with 19 years of work experience)

Proprietary form: The inpatient or outpatient information is a very important resource for research and therapeutic follow-ups. Based on data analysis and the experiences of participants, the use of proprietary forms for gathering the data from patients with RA facilitated review and access to patient information.

(P2): "*In the case of developing a proprietary computerized form that includes details related to examination, tests, medications, and treatment process, the registration of patient data based on disease activity score may speed up data entry.*" (A 40-year-old female rheumatologist with seven years of experience).

1.2. Software: This category indicates a set of elements

Table 1. Variable, Category, and Subcategory

Variable	Category	Subcategory
Physical	Hardware	Space and equipment
		Proprietary forms
	Software	Infrastructure
Financial	Financing	Supporting research using registry system
		Paying equal attention to treatment centers
Human	Skilled personnel for RA data entry	Holding workshop
	Tendency of more specialists to perform medical treatment	High frequency of patients' referral
		High frequency of referral of patients to specialists
Managerial	Lack of referral system	
	Support of Ministry of Health	Monitoring integrity of RA data
		Effective communication between academic hospitals
		Instructions for registration
Time	Lack of time	Allocating time to health and education

including rational infrastructure, computer programs, and guidelines for collecting and integrating data related to patients with RA. The infrastructure subcategory was considered for the software category.

1.3. Infrastructure: A set of computer networks which encompasses feasibility and primary design and monitor and run different parts of the registry system (i.e., network protocols, remote access, and security) for patients with RA. The collection, analysis, publication or reporting in addition to follow-up of treatment results and data security require the development of a web-based electronic system.

(P5): *"In the case of the lack of a standard infrastructure for registration, the collected data may not be analyzable or evaluable."* (A 55-year-old male rheumatologist with 18 years of work experience).

2. Financial

The financial support is one of the crucial factors for achieving the health goals and ensuring the funding is an engine for triggering RA registry system. The majority of participants in this study emphasized the need for financial support to resolve the challenges of creating a registry system for RA. Two subcategories including budget allocation and research support were highlighted for this category.

2.1. Financing: The disease registration system plays an important role in the better understanding of diseases, controlling deaths, and reducing the burden of diseases. Despite these advantages, the interviewees emphasized the lack of support for launching such a system.

(P9): *"I suggested rheumatologists employ a fixed employee for the entry of data registration, and they indicated that the research and technology deputy at the university should finance the budget."* (A 52-year-old female rheumatologist with 19 years of work experience)

Research support: The disease registry plays a major role in promoting medical knowledge, along with new achievements in the field of diagnosis and treatment.

In the case of launching RA registry system, the rheumatologic research may be supported quantitatively and qualitatively.

On the role of registry in research, the interviewee #8 stated that: *"The accurate statistics about patients, treatment-resistant cases, the geographical distribution of disease, the side-effects of biologic drugs in different people, the signs of disease in different races (considering different ethnic groups in Iran), and the like may be achieved through RA registry. This will directly affect the research and prevention of rheumatic diseases."* (A 52-year-old male rheumatologist with 18 years of work experience)

Allocating equal budget to health centers and satisfying rheumatologists' demands: Allocating equal funding for research to educational-medical centers and timely satisfying the rheumatology specialists' demands may be effective factors in conducting research activities and having a tendency to register. Based on data analysis, the interviewees believed that the research budgets should be distributed equitably and based on real needs in different health centers.

(P9): *"The health officials should supervise all health centers at the same level and equally allocate budget for research works. Sometimes, they spend a lot of money on some studies, but they disagree upon funding the research which may have benefits for the patient, doctor, and health system."* (A 52–year-old female rheumatologist with 19 years of work experience).

3. Human Resources

They are one of the most important assets of organizations. The data analysis showed that the lack of attention to employment and the shortage of manpower are the other challenges of creating and launching the registry of RA.

3.1. Employing human resources for entry of RA data: The organization of qualified and trained personnel for registration of patients with RA should be considered. The data registration is a continuous process, so it is necessary

to employ a constant workforce with sufficient knowledge who will be responsible only for entering RA data.

(P9): *"If data entry of patients has different interventions, this may lead to bias or lack of integrity and uniformity of information. This may affect patients; they will not know what medicine they have taken on their previous exam and when is their next visit."* (A 52-year-old female rheumatologist with 19 years of work experience)

(P8): *"One of the problems is that those who enter the registration data discontinue registering data for other patients after the end of the study. It is also possible that the registration employee continues the vacation or moves to another part. Thus, the registration of the data will be incomplete."* (A 52-year-old male rheumatologist with 18 years of work experience)

Holding workshop: The life skills training aims to improve the physical, psychological, and social abilities of patients and thus to promote health in patients with RA.

(P9): *"In some countries, patients play a more active role. For patients' participation and intervention, the social associations should hold workshops to empower patients, make them active, train lifestyles, show the side effects of drugs, and display movies on doing useful activities to increase life expectancy."* (A 55-year-old male rheumatologist with 18 years of work experience).

3.2. Tendency of most specialists to conduct treatment: The rheumatologists are not motivated to participate in the registry due to their multiple tasks and only provide patient treatment or training.

High frequency of referrals: The waiting time for a patient's visit with a doctor is one of the indicators of their access to health services. The large number of patients and the continuance of treatment by rheumatologists make these specialists more willing to perform treatment actions rather than spending time for data registration.

(P1): *"The registry of patients' data by rheumatologists is a time-consuming process and is only conducted by specialists who perform scientific works. Most colleagues perform healthcare actions rather than research works."* (A 40-year-old female rheumatologist with 8 years of work experience).

4. Management
Scientific management is required to promote patients' health. The effective management was another subcategory which was identified by data analysis It was found necessary for the registry of RA data as well.

4.1. Referral system: The interviewees considered the failure of the referral system in Iran as one of the factors which complicated the registry of RA.

4.2. Support from and supervision by the Ministry of Health: The disease registration necessitates a specific management structure which includes registration authorities and committee. In this study, the interviewees mentioned that management plays a supportive role in the registry of RA data.

Monitoring the integrity of RA data: High-quality data should have important features such as completeness, timeliness, and comprehensiveness. The participants believed that the integrity of data should be taken into consideration for achieving registration goals such as patient survival analysis.

(P8): *"Physicians are encouraged to complete the information and register patient's data completely and accurately if their prescription approval by the insurance centers depends on the completion of outpatient and inpatient data."* (A 52-year-old male rheumatologist with 18 years of work experience).

Effective relationship between academic hospitals: The establishment of a registry system is prevented by several factors such as unhealthy competition, uncertainty in sharing patient data due to scientific competitions, and the lack of coordination among academic hospitals which treat RA patients.

The interviewee #8 expressed his perception of the monitoring role of the Ministry of Health in the effective communication of hospitals as follows.

"The Ministry of Health has access to all medical universities and thus can present a legal registry system for all universities, manage data, and finally, provide databases in the cities. Therefore, the problems of the lack of confidence in universities and not sharing the registry data are resolvable." (A 50-year-old male rheumatologist with 15 years of work experience).

The lack of instructions for registration: Determining data entry responsibility and the conditions of specialists' access to data may accelerate the registration of RA data.

The high frequency of patients' referral to specialists: In this study, the lack of a proper referral system in the healthcare process, as well as the absence of general practitioners' attention to RA patients' referral to rheumatologists led to the high-frequency referrals of patients to the specialists.

(P1): *"The referral system would make high-level centers to have less workload. This may prevent overcrowding in the main centers while providing the chance for the referral of those patients with real needs."* (A 40-year-old female rheumatologist with 8 years of work experience).

Time
In Iran, some doctors have administrative responsibilities in addition to their roles as practitioners. Based on data analysis, the lack of time to address the creation of the registry system was found to be the last subcategory.

Allocating time for treatment and training: The high requests for a visit make the patients wait a long time which reduces the quality of service. On the other hand, the creation of a registry system for RA requires allocating the intended time. However, the majority of participants complained about the lack of time.

(P2): *"In addition to examining the patients, I should also train the residents to accurately perform their responsibilities. Thus, I have no time to register the data."*

(A 40-year-old female rheumatologist with 7 years of work experience).

Discussion

The findings showed that the health outcomes and disease registration program are placed on the agenda of the Ministry of Health as an important infrastructure for the development and enrichment of medical science research in Iran (10). According to Zare et al, most developed and developing countries require setting up an information registration system in order to meet their needs and promote the health level (13).

They further indicated that the system for registering the cancer patients' data is necessary in Iran. As regards the infrastructure, such a system can provide different services to all laboratories, pharmacies, and doctors for monitoring their patients' health status (13).

Similarly, Zhang et al studied the situation and challenges of patient's registry in China and found that the allocation of benefits to various stakeholders is regarded as one of the greatest challenges of registry in this country. This problem may be solved by designing and establishing a set of motivational mechanisms. China has enough data which can be extensively used, but the heterogeneity of the registered data limits its use. Furthermore, the registry in China requires a high-quality standard transfer and coordinated development (14). Likewise, a national and effective registry system (compatible with necessary standards) in Iran may provide useful findings in various fields such as the consequences of using biological drugs or the incidence of diseases in various geographical areas.

In another study, Blumenthal referred to the lack of access to registry information at a wider level by investigating the use of clinical registries in the United States. Despite the fact that the use of clinical information is increasing to improve value-based payments, he introduced interoperability as a challenge in the registry even in national registries which use standard data. Moreover, Blumenthal mentioned the barriers to structure and organization of the US registries as the sustainability of long-term registry plan, the related costs, and interoperability. He also identified other challenges in the US clinical registries such as legal issues related to collecting data on patient-reported outcomes and legal requirements in dealing with participants at the registry (15).

The established national registries in America include standard data, but they are not linked with each other and have no access to external data such as publicly-available reference datasets. In 2015, there was an increasing demand to link the registries with other data systems. In other words, the development of interoperability metrics required the data related to multiple registries (15). The study of these challenges in the leading countries in establishing disease registry systems may provide useful information for the successful implementation of a disease registry system in Iran.

In a qualitative-comparative analysis study, Holtrop et al highlighted factors affecting the successful implementation of a registry system. He believed that establishing, refining, and updating disease registries, and finally, integrating these registries with e-records is time-consuming and frustrating. According to Holtrop et al, the delay in setting up effective and actionable registries is a success in trying to improve the quality of care. Additionally, he identified the health system, key individuals, quality improvement mindset, quality improvement, leadership, and motivation as contributing factors in the success of registry implementation (16). Although there are disease registration programs which provide opportunities and achievements for the health system in Iran, they still require the financial and spiritual support of the Ministry of Health, as well as medical science universities (17).

In a qualitative study, Mandavia et al proposed the requirements for successful development of a registry system for hearing implant in the United Kingdom as a conceptual framework. These requirements included planning, registry office and dataset, predicting challenges, and executive solutions. In this study, the data were collected by interviewing qualified specialists and using the focus group of hearing-impaired patients. The above-mentioned study differed from the present study in some aspects such as data collection and research method. In the current study, the main stakeholders were rheumatologists who used RA registry and no patients were included in the study due to the lack of knowledge about the registry system while Mandavia' method and protocol varied from those of the present study. Further, the approach in this study may be used for international announcement while Iran has a long way to run its registry plans (18).

Furthermore, Yörük examined the challenges and opportunities of a disease registry in Turkey by focusing on rare diseases and oncology. To this end, she focused on protecting participants' privacy and providing political and technological solutions for global collaboration in order to achieve data which is consistent with the standards and standardization provisions. This may improve the efficacy of disease registries for application in research and the collection of larger population-based statistical data (19).

The observational studies of valid disease registries provide valuable data on the incidence rate and quality of medical care which the researchers and decision-makers can employ to fill the gaps. These data also help the researchers to diagnose medical necessities.

A highly qualified registry system is also essential for the advance in precision medicine with a bedside-to-bench concept by the gathered data from well-designed and more controlled observational epidemiological or pharmacoepidemiological studies.

The development of common data elements for the standardization of the collected data in registries may overcome the issues of missing or misinterpreted data. Moreover, a standardized statistical design is needed

to control the missing data and potential biases which naturally occur in observational studies (19).

In a study on the discontinuation of using biological drugs, Yoshida et al investigated the challenges and opportunities of using data in multiple registries and identified six challenges in the data combinations of multiple registries as follows.

- The generalizability of registry;
- New versus prevalent user designs;
- The description of the consequences;
- Different healthcare systems;
- Different follow-up intervals;
- Synchronization.

The first three cases were associated with registry usage and the remaining cases referred to registry combinations (20). As previously noted in this study, comparing the effects of the discontinuation of using biological drug among the patients may be one of the applications of RA registry, which physicians may take into consideration when making decisions. The research questions require generalizable clinical information and high sample size which are regarded as the characteristics of dataset combination. In Iran, the disease registry system, in general, and RA registry, in particular, are designed to address the challenges which occur quantitatively and qualitatively. The training and empowerment of the experts and managers of the registration program should be emphasized as well. Likewise, the avoidance of research centers, universities, and the executive headquarters of the Ministry of Health from parallel work over the past few years has provided a platform for the sustainable development of disease registration infrastructure and activities.

The information exchange is required for the registration of different diseases in Iran based on the registry of the pioneering countries. Therefore, it is necessary to develop standards, protocols, and technical mechanisms for data exchange and this may be realized in cooperation with the experts (17).

The national program for the registration of certain diseases in Iran is in its initial steps. The main future challenge of this program is the adequate funding and ethical issues in using the data related to these registries (10). The report failed to mention the challenges of RA registry.

Although Iran is at the early stages of disease registry, the developed countries such as Scandinavian Chatzidionysiou emphasize the growing need for accurate information on rheumatoid diseases. A study was conducted to create a network-based registry in Sweden, Denmark, Finland, Norway, and Iceland for performing clinical research on various types of rheumatic diseases. In these countries, the registry of RA began in 1999-2007 thus they faced no challenges regarding creating the registry systems as compared to Iran (21). Several studies evaluated the effects of biologic drugs on patients with RA using a registry system (22-25). Contrarily, no study has confirmed the use of registry in research in Iran.

Conclusions

In general, although the number of participants was acceptable in the present study, rheumatologists were limited in terms of having both the clinical expertise and registries as an information system.

Based on the findings, the current study attempted to examine the challenges of creating a registry system for patients with RA, as well as various diseases including RA which is considered as one of the missions of the Ministry of Health. Therefore, policy-making and planning at various levels require integrated, comprehensive, accurate, and up-to-date information. The registration of RA patients is not timely and online since there is no integrity between the relevant units which are responsible for providing services to patients in Iran. The doctors and health planners should focus on the identified challenges in making decisions about setting up and creating a registry system. Finally, an appropriate system for the registration of disease data may have many benefits for the healthcare system and more importantly, for patients with RA.

Conflict of Interests

Authors have no conflict of interests.

Ethical Issues

This study was approved by Ethical Committee of Iran University of Medical Sciences (IR.IUMS.FMD.REC 1396.9223668203).

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