

Analysis of Infertility Electronic Registration System Data Elements A Comparative Study

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ABSTRACT

According to increasing of infertility in Iran and importance of identifying factors affecting infertility and its costs, the aim of this study was analysis of data elements of infertility registration system in Iran and comparison with other leading countries in this regard. This is a descriptive-comparative study and was done in 2015. Research resources were Infertility registration system in America, Britain, Australia, Belgium and Japan, which were retrieved from the Internet and also documents, forms and systems in Iran. These data were entered in data extracting form. Then, data elements of the Iran and selected countries were compared and the results were presented in descriptive tables. The results of this study were divided in three categories and each category has some sub-categories. First category was included demographic information of patients and physician, in second category, there was some information such as menstrual status, sexual, reproductive history, medical history, surgery and medication. Also, the third category was included causes of infertility, male and female infertility tests and treatments. According to the increasing prevalence of infertility in Iran and the absence of a comprehensive infertility registration system, need to develop a comprehensive registration system is clear. Also, update and add new variables to improve the system are recommended after launch.

Key words: electronic registration, infertility, registration system.

INTRODUCTION

In today's society most of the information required by the country's health system, is related to health information. So all health activities would be documented and recorded manually or computerized. Registry system, is a set of patients, related data with a particular diagnosis or a specific

action. Activities such as tracking patterns of referral chain of patients, evaluation and follow-up processes of quality of patients care, providing essential data for valuable sources of health care systems executive planning and hospital program marketing will be possible by efficient registry system^{1,2}. It is evident that a large amount of documentation related to patient's diagnostic and

therapeutic care is stored in health care centers. The total medical records that information, such as numerical results of the laboratory tests, the symptoms and images of each patient is saved on it, make up the core hospital information system⁽³⁾. Health care systems requires accurate estimation of the size of public health problems in order to plan to meet future needs accurately and precisely.

Infertility is one of the common problems of human society⁴. Infertility definition according to the World Health Organization is known as "reproductive system diseases with the failure to achieve pregnancy after 12 months or more of unprotected sexual intercourse"⁵. Infertility, in today's world has become as one of the medical problems and a social concern. This event is an exciting and frustrating circumstances for couples and is associated with social, emotional, physical and financial consequences^{4,6}. The other factors that affects many under treatment couples, are the imposed medical care costs, lack of adequate insurance coverage. Infertility etiology is different and its trend may be affected by various environmental, and genetic factors. Even with the current therapies, all infertility cases are not treatable, it has been reported that infertility causes in 40% of subjects are related to female factors, 40% are male factors and 20% are common factors^{7,8}.

According to the World Health Organization report, over 70 million couples around the world and more than 1.5 million couples in Iran are suffering from this problem⁴. Long course of medical care compared to affected population in Iran, patients socio-economic class which mostly belong to low-income category, the relatively high cost of medical care and increasing growth rate of aging population are among the matters which has made the disease noteworthy⁹. Population-based studies are a good way to evaluate the prevalence of infertility. Several studies have been conducted to determine prevalence of infertility in the different communities and different results have been reported. The rate have been reported in China about 3%, in Scotland 14% and in the Sheffield, Britain about 30%^{4,10}. Several studies have been conducted to determine the infertility prevalence in Iran and the results were different. About one-fourth

of the Iranian couples experience primary infertility during their married life, and 3.4% of couples are suffering from primary infertility at any time¹⁰. There is a little accurate information about the prevalence of infertility in Iran right now. It seems for effective health care planning and for better understanding the problem, it is important to know this information in a systematic manner. Despite the positive changes in many areas of health care system in the last 3 decades in Iran, little attention has been paid to the issue of infertility data collection and infertility registration national system based on international standards.

Due to the increased infertility prevalence, it's different definitions, and multiple estimations of emotional, financial burden of disease on infertile couples quality of lives, as well as improper quality of medical care services, absence of a coherent national registration system, and since knowing exact pattern and infertility prevalence rate, is one of the indicators for health and family planning, we decided to examine the national registry system structure in the developed countries and compare it with the infertility clinics data in Iran in order to provide strategies for creating an electronic registry system and unique definition.

MATERIALS AND METHODS

This was a comparative cross-sectional descriptive study that conducted in 2015. The research data resources were included retrieved infertility registry system and documents from the websites of the United States, United Kingdom, Australia, Belgium and Japan. Selecting criteria of these countries was the possibility of access to their documents and being pioneer in the infertility medical care and interventional procedures. In this section, sampling was not done and all systems were reviewed. In these countries the retrieved documents was based on inclusion criteria. The inclusion criteria was included: retrieved literature in English, access to full texts which was published from 2000 to 2015 and also receive definition and components data via e-mail from the web-site managers. Resources for Iran was the research website, public and private documents and paper files of the infertility clinics in Tehran (10 centers), respectively.

Based on the literature review data collection tool was, a data extraction form that developed by literature review and previous studies on data elements of information systems determining. Data extraction form was divided in to three main sections that included, basic patients information, past medical history and medical plan based on the initial retrieved literature website review, experts view in the field of the infertility, Ministry of Health experts and health information management experts.

Iranian and selected countries' websites and documents were examined. Data were extracted and entered on separate forms for Iran and each other country. Then the data was integrated and provided as a list. Selected countries, data elements were translated into Persian. The final data elements content validity was confirmed by seven experts (three PhD in Health Information Management, three infertility specialist and one community medicine specialist). Then six columns in names of countries were placed in front of each data element, and availability of each data element was determined according to preliminary data elements extracted from the country. At last data elements were compared and presented in descriptive tables.

RESULTS

According to conducted survives in the countries, studied systems as well as the infertility clinics in Iran, the results were divided into three categories that have been mentioned in the following table.

DISCUSSION

Due to our society cultural structure, infertility takes a deeper dimension, and could be considered as one of the reasons for divorce. Thus infertility is associated with many social aspects. The infertility medical care cost is another important issue that will affect the individual⁴. Therefore, existence of an electronic registry system that includes different aspects of infertility and be helpful in terms of medical and economic that is crucial. Researchers believe that preventive and Continuous Quality Improvement plans development, health

care costs estimation, productivity, epidemiological studies, decision-making, organization, planning is not possible, without a comprehensive, structured and valid registration system. Due to its importance, design and implementation of an infertility electronic registration system is priority of health systems in many developed countries like the United States, United Kingdom, Australia, Belgium and Japan. Surveys carried out in Iran, confirms that infertility contraceptives and management faces challenges due to lack of access to related data⁽²⁾. Accordingly, in this study data elements from infertility health care centers compared with entered data elements of infertility electronic registration systems of United States, United Kingdom, Australia, Belgium and Japan.

Comparison of patient basic information and infertility health care centers in Iran with the mentioned countries registry systems were shown in table 1. Several factors of demographic data were examined. One of these factors, was individual age at onset of treatment. Because of importance of reproductive age and its effect on oogenesis & spermatogenesis in female and male, as well as the production of healthy sperm's genetic repair system, it seems to be very important to be examined. It is recorded in the America and Japanese system too^{11,12}. Racial investigation was recorded in the USA and UK infertility registry system due to large genetic differences resulted from immigration and breed difference^{11,13}. Racial differences was not recorded in Iranian clinics. But according to Iran's vastness and different ethnic groups with different genetic predisposition in the country, it seems to be an essential and a future need. Since family relationship of the couple can affect fertility genetically, it were present in information extracted from the Iranian clinics. The consanguineous marriage is not common in other countries, this is not mentioned in the other studied countries results. Due to the social and religious norms in Iran that sex and childbearing only is permitted in marriage the "relationship of men and women" element did not exist in information obtained from Iran. "Marital status" element did not exist in Iranian infertility registry system recording, but is recorded for female in USA, UK and Australia registry system^{11,13,14}. Recording "length of marriage" element is important to understand the active

Information	Patient Insurance			*	*	*	*
	Use of governmental support system for ART	*					
	Physician Name(firstname & (Surname			*	*		*
	Address			*	*		*
	Phone(Telephone)			*	*		*
	Provider no.			*	*		*
	email			*	*		*
	Specialty					*	*
	In case of emergency notify:Phone					*	*
	Need to interpreter				*		*
	Patient's Signature					*	*
	Date		*			*	*
	Partnre/Spouse's Signature					*	*
	Date					*	*
	Donor number,	*	*	*			
	Date(s) of donation(s),						
	Date gametes produced for use,						
	Any donations at other centres,						
	Marital Status						

pregnancy prevention and documented for USA and Iranian female clients ⁽¹¹⁾. Infertility period “element means not childbearing, despite having sex intend to be fertile. This element is very important in disease prognosis and better medical care solutions. This data element was part of infertility registry system in Iranian and UK systems ⁽¹³⁾.

In Table 2 which includes the history section several factors were examined. One of these elements was “menstrual cycle” Which is important in terms of regularity, which its causes could be different and determining them is effective in treatment processes. This item was available in Iran’s website, and also were listed in the in Australia, USA and UK system ^(11,13,14). Information related to the “live birth numbers element” was recorded in Iranian clinics, this element can show the individual ability for productivity, regardless of genetic or newborn disease or prematurity . This element was not mentioned in the studied country registry system and could be due to differences in

the data entry. “Abortion (intentionally or unintentionally) and the Ectopic Pregnancy” Elements were presented in obtained information from Iran and also existed in USA and Australia registration systems ^(11,14). “Contraception” element is also important due to the effect on selecting choice medical care plan. This element is exist in extracted information from Iranian men and women, however in USA and Australia it is just indicated only for women, which could be due to social and cultural differences in the one of the spouses contraceptive methods selection ^(11,14). Also different kinds of medications and reproductive health practices have been mentioned in USA system that because of multiplicity, it has not been investigated in Iran ⁽¹¹⁾. Due to the impact of overweight and obesity factors and its consequences the “weight” in Iran, USA, UK and Australia are listed. To calculate the body mass Similar to Australia, USA and UK “The height” of individuals were existed in Iranian information ^(11,13,14). Some underlying disease were also investigated, for example, “diabetes” that effect on

Table 2: Shows the patient, past medical history , sexual behavior , previous obstetric history, previous treatments and

Data element	country	Japan		Belgium		United kingdown		Australia		United States		IRAN	
		M	F	M	F	M	F	M	F	M	F	M	F
Age of Menarche(Menstrual onset)						*				*		*	*
Menstrual cycle pattern						*		*		*		*	*
Length of flow/ days of bleeding						*				*		*	*
Period Flow						*		*		*		*	*
Number of days between the start of one period to the start of another						*		*		*		*	*
Bleeding between cycles						*		*		*		*	*
Postcoital Bleeding						*		*		*		*	*
number of vaginal bleeding in the year						*				*			
Last Monthly period/ LMP(last menstrual period)/Previous Menstrual Period				*		*		*		*		*	*
change in any way over the last 2 years in your period								*					
pass clots? every cycle?										*			
Molimina										*		*	*
Menstrual pain or cramping/ Dysmenorrhea.								*		*		*	*
Pain medication for cramps										*			
severe cramping or pelvic pain with periods										*		*	*
constipation or diarrhea associated with periods										*			
Periods after stopping the oral contraceptives medication (birth control pills)										*			
Can you tell when you ovulate? -- How?										*			
Bleeding after menopause										*			
Amenorreh										*		*	*
Oligomenorreh												*	*

Menstrual

Premature Menopause		*				
Sexual	pain sexual intercourse (Dysparonia)	*	*		*	
	lubricant or grease for sexual intercourse	*	*		*	
	Discharge		*		*	
	Frequency of Coitus per week	*	*	*	*	
	Douches(vaginal douching) before or immediately after intercourse	*	*		*	
	Get out of bed after intercourse			*		
	problems with initiating or completing sexual intercourse	*	*	*		
	plan intercourse for a specific time of cycle			*		
	Male problems		*			
	your mutual sex life			*		
	sex with your partner			*		
	your fertility problem is			*		
	Previous fertility Hx	Total Number of ALL pregnancies	*		*	
		previous natural pregnancies	*			
Number of Full Term Deliveries				*		
Live Birth					*	
Number of Miscarriages/ Abortions		*		*	*	
Number of Elective Terminations		*		*		
Number of Ectopic/Tubal Pregnancies (E.P)		*		*	*	
Number of Preterm Deliveries (less than 37 weeks)				*		
pregnancies with birth defects				*		
Knowledge of Frtile ages				*	*	
Number of & ages & sexes living children(No of children) in Current relationship		*	*	*	*	
Largest child at birth				*		
Smallest child at birth				*		
Child with another partner/Number of Children in Previous relationships		*	*	*		
Abortions					*	

	Galactorrhea				*	*
	Heart Disease/Heart Murmur				*	*
	Hepatitis				*	*
	Hirsutism				*	*
	HIV/AIDS				*	*
	Kidney or Bladder Disease				*	*
	Neurological Problems				*	*
	Obesity				*	*
	(PID (Pelvic Inflammatory Disease				*	*
	Respiratory Disease					*
	(STD (Sexually Transmitted Diseases				*	*
	Thyroid Problems				*	*
	Tuberculosis				*	*
Past Surgical Hx	Year, Reason and Type of Surgery				*	*
	Medication Type				*	*
Medication	allergic to any medications					*
	any over-the-counter medication on a regular basis					*
Lifestyle	Exposed to chemical or x-rays in work or hobby				*	*
	Exposure to prolonged hot baths, saunas, steam baths				*	*
	Exposure to radiation or chemicals at the workplace/ use hot tubs regularly				*	*
	Exposure to prolonged hot baths, saunas, steam baths				*	*
	Cigarettes				*	*
	cial dietary habits/ Illicit or Recreational ugs/ Alcohol/ Nutritional supplements				*	*

		T.B										*
		<hr/>										*
Allergy												*
Renal DZ.												*
Epididymitis												*
Fresh Embryos From Non-Donor Eggs	Number of cycles, Cycles resulting in pregnancies, Cycles resulting in live births, Retrievals resulting in live births, Transfers resulting in live births, Cycles with elective single embryo transfer, Cancellations, Implantation Rate, Number of embryos transferred, Live births with twins, Live births with triplets or more	*	*	*	*	*	*		*	*		
	Number of Transfers, Transfers resulting in live births, Average number of embryos transferred, Number of cycles, cycles where thaw was attempted that resulted in live birth					*	*		*	*		
Thawed Embryos From Non-Donor Eggs	Age of oocyte/embryo donor, Date of intra-uterine insemination, Number of Cycles, Recipient starts resulting in live birth, Number of Transfers, Transfers resulting in live births, Average number of embryos transferred		*	*	*	*	*	*	*	*	*	
	Unique identification of each cycle											*
The date the cycle started												*
Surrogacy arrangement												*
FSH stimulation												*
OPU(oocyte pickup) date												*
Number of eggs retrieved		*					*	*				
Number of eggs donated												*
Number of eggs IVF												*
2pn – IVF												*
Number of eggs GIFT												*
ZIFT												*

PESA		*
TESA		*
IUI cycle	*	*
Long cycle	*	*
Natural Freeze cycle	*	*
Mix cycle	*	*
Antagonist cycle	*	*

internal organs and even sexual organs indirectly and cause infertility and miscarriage. It is listed in Iranian, USA and Australia systems^(11,14). The "Tuberculosis diagnosis" obtained from studies of Iranian clinics as well as USA website, due to the high incidence rate of the disease and its effects on internal organs⁽¹¹⁾. Another issue related to women's infertility is "Endometriosis" that because of the rising trend in Iran, was considered in conducted studies of Iranian clinics as well as in USA and Australia systems^(11,14). "Galactorrhea" or withdrawal of milk from the breast ducts without labor are signs of infertility and hormonal disorders. As well as "Hirsutism" in women could also be another sign of hormonal disorders. "Thyroid disturbances" is among other hormonal disorders. All of the above mentioned elements was gathered from infertility clinics information in Iran also presented in the USA system⁽¹¹⁾. Stressful situations, "neurological problems" that effected on various parts of the body also affects fertility that regarding to Iranian living condition was investigated and also existed in USA infertility registration system⁽¹¹⁾. But this issue has not mentioned in the UK, Belgium and Japan systems that could be due to differences in lifestyle and socio-economic conditions^(12,13). Due to the spread of self-medication and OTC administration in Iran, taking "OTC medicines," was an important item to Iranian clinics, but it wasn't in the UK, Japanese, Belgium and Australia systems⁽¹²⁻¹⁴⁾. Due to the prevalence of "substance abuse" (cocaine, heroin and marijuana) in USA and its impact on infertility, data was obtained in USA national system⁽¹¹⁾. Although

"substance abuse" element in Iran, is not very common, but for better result it has been taken in Iran. Due to high rate of "smoking" in our country as well as Australia and USA systems, smoking is investigated in Iran and USA & Australia^(11,14). Also "liquor use" due to religious factors is not common in Iran and was not considered in infertility clinics studies, while it is listed in the USA and Australia systems^(11,14). Part of the care program, is about the "infertility causes". The infertility etiology is various and is including factors related to fallopian tubes, infertility caused by the abnormal presence of uterine lining tissue outside the uterus in women and sperm parameters as male factor. These factors were on website of all studied countries, as well as information obtained from Iran's⁽¹¹⁻¹⁴⁾. Regarding the above mentioned items and the growing trend of infertility in the country, there is necessity of an integrated infertility registry information system in Iran. A system that fits the norms of our society and cultural condition, help to improve the clients/patients medical care condition, reduce the imposed costs, and due to the information s comprehensiveness, even is important for future researches.

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REFERENCES

1. Ghazi Saeedi, M., Davarpanah, A., Safdari, R. Health information management. *Tehran: Mirmah*. 256-8 (2007).
2. Keyvanara, M., Sadeghi, M., Isfahani, S.S., Tadayon, H. A comparative review of national registry systems of acute coronary syndrome in selective countries. *Director General*. 9(2) (2012).
3. Delamarre, D., Burgun, A., Seka, L.P., Le Beux, P. Automated coding of patient discharge summaries using conceptual graphs. *Methods Inf Med*. 34(4): 345-51 (1995).
4. Delpishe, M.A., Moradi, Z., Moghadam, N.M. Aspects of epidemiology of infertility in Ilam in 2013. *The iranian j obstetrics. gynecol infertil*. 17(98) (2014).
5. Van den Broeck, U., Spiessens, C., Dancet, E., Bakelants, E., Vrancken, A., Demyttenaere, K., et al. Patient evaluation of infertility management in an ISO 9001certified centre for reproductive medicine. *Reproductive biomedicine online*. 24(3): 293-300 (2012).
6. Yeylaghbigi, M., Mazaheri, M., Taher Neshatdoost, S., Manshai, G., Talebi, H. Investigating Changes in Anxiety and Emotion Among Women Under IVF-ICSI Therapy. *Journal of Guilan University of Medical Sciences*. 23(90): 32-41 (2014).
7. Hasanzadeh, L., Tarkhan, M., Taghizadeh, M. Effectiveness of stress inoculation training on perceived stress in pregnant women with infertility.
8. Nouri, R.K., Akhondi, M.M., Ardekani, Z.B. Psychosocial aspects of infertility from viewpoint of infertility treating physicians. *Journal of Reproduction & Infertility*. 2(3) (2001).
9. World Health Organization. Women and health: today's evidence tomorrow's agenda: World Health Organization (2009).
10. Derikvand Moghadam, A., Sayehmiri, K. The Prevalence of Infertility in Iran, A Systematic Review. *Iran j obst gynecol infertil*. 16(81): 1-7 (2014).
11. Mansour, R., Ishihara, O., Adamson, G.D., Dyer, S., de Mouzon, J., Nygren, K.G., et al. International Committee for Monitoring Assisted Reproductive Technologies world report: assisted reproductive technology 2006. *Hum Reprod*. 29(7): 1536-51 (2014).
12. Saito, H. ART registry system and present status of ART in Japan. *Acta Obstet Gynaecol Jpn*. 62: 739-45 (2010).
13. Ferraretti, A., Goossens, V., Kupka, M., Bhattacharya, S., De Mouzon, J., Castilla, J., et al. Assisted reproductive technology in Europe, 2009: results generated from European registers by ESHRE. *Hum Reprod*. 28(9): 2318-31 (2013).
14. Macaldowie, A., Wang, YA., Chambers, GM., Sullivan, EA. Assisted reproductive technology in Australia and New Zealand AIHW; 2013 (2010).