

ART Registries–Characteristics and experiences: A comparative study

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ABSTRACT

Background: The incident of infertility is continuously increasing. As a result, the demand for medical care such as assisted reproductive technology (ART) technology is equally increasing. In order to manage the growing data and information collected on ART, there is a need for a registry system can provide accurate statistics about activities and outcomes and ensure the quality control. Therefore, the aim of this study was to examine and compare In vitro fertilization (IVF) and ART registries. **Methods:** This is a descriptive-comparative study in which data from the national ART registries of 14 selected countries in 2018 were collected. In this study, databases such as PubMed, Web of Sciences, and Scopus, as well as Google Scholar websites were searched. **Results:** Important aspects of the registry were studied. One of the most important goals of these systems is to collect information about ART, as well as to monitor and report the results and implications, and also implement new care plans. **Conclusion:** A national registry helps to better understand the scope and the effect of assisted reproduction on the health of infertile couples. By this registry system, different countries can compare the data with other countries, allowing the improvement of techniques and the best possible care for patients.

Keywords: ART registry, infertility, information system, IVF registry, registry system

Introduction

Infertility is one of the most important health problems in all societies and all ages.^[1] It is also one of the most important challenges of human life.^[2] Estimates suggest that by 2025, about 70% of couples will be affected by infertility. The incidence of infertility is increasing day by day, and this may be due to various reasons, such as sexually transmitted infections, stress, work pressures, urbanization, obesity, etc.^[3] Infertility has many effects on health of infertile couples. Infertility is one of the most important causes of depression and its consequences range

from fear, depression, and social isolation to violence and suicide, it also affects the life satisfaction.^[2,4-8] Infertile women similar to cancer patients or patients with heart failure may encounter some level of distress.^[9] The Centers for Disease Control and Prevention (CDC) has introduced infertility as a “public health priority” in the United States and has subsequently created an initiative to identify, prevent, and manage the infertility.^[10]

As a result of this demographic process, the demand for medical care is equally increasing and there are various types of health care such as assisted reproductive technology (ART).^[11] ART has become increasingly popular in the world.^[11] One of the most important challenges of managing the growing data is collecting reliable data on ART at a large scale and providing a computer

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data collection system for controlling and organizing these treatment cycles to reduce potential risks.^[11,12] The disease or patient registry is a rich source of information for every health care decision making, which contains supplementary sources of data and provides information on the “real world” activity and the effectiveness of treatment and methods.^[13] A registry system can provide accurate statistics on the activities and consequences, and ensures the quality control.^[14] The registry plays an important role in providing information to the public, patient, policy makers, and the scientific community. The results of medical activities should be collected, processed, documented, and evaluated.^[15] These data are important in monitoring ART activities, ART results and implications at the national level to identify the availability of ART clinics, the effectiveness of treatment and safety of ART methods. They also provide a strong information database for education and development of ART policy.^[16] The purpose of this study was to review and compare IVF and ART registries including objectives, data sources, responsible organization, and information elements of these systems in selected countries.

Methods

This study is a descriptive-comparative in which, the data were collected from the national ART registries of selected countries in 2018. In this study, databases such as PubMed, Web of Sciences, and Scopus, as well as Google Scholar websites were searched. Keywords; IVF registry, ART registry, Infertility, and surveillance were used along with the names of countries.

In this study, data from leading countries in the ART registry program were categorized according to the world's continents. From America, United States, Canada, and Latin American countries; from Europe, Belgium, Denmark, Germany, France, Switzerland, and Italy; from Africa, South Africa and Egypt; and from Asia and Pacific, Australia, New Zealand, Japan and India were selected. Then, the articles related to the purpose of the research were selected and sorted according to the name of the countries. Finally, the comparative results were summarized in Table 1.

Results

Due to the increase in ART treatment in the world, there is a need for reporting and analyzing ART data of different countries. Today, some countries have established a registry system to evaluate and monitor the effectiveness of treatment, implications of pregnancy, and health of treated women.^[11] For this purpose, the present study examined and compared the ART and IVF registry systems of selected countries. According to the studies, one of the most important goals of the registries is to obtain and provide statistical purposes for diseases in order to plan for the future. As long as there is no valid and reliable statistics on a disease, it is virtually impossible to decide and plan for its management. Another goal is to evaluate the effectiveness of treatments, to analyze important factors, monitor the results, compare them with previous results and achieve the

success rate of the methods used. Also, the most important information that is recorded in the country's registry systems include the patient's demographic information, medical history, patient's pregnancy, the diagnosis and causes of infertility, cycle information and various ART methods, ART complications, number of transmissions, results of pregnancy, deliveries, and childbirth information. The results also showed that information on anomalies and abnormalities is recorded in Germany, Latin America, Egypt, and India. Information about the donation of oocytes is not recorded in Egypt, unlike India. Recording of information by ART clinics is mandatory in Denmark, Italy, Australia, Japan, and India.

Discussion

To have an effective health care system, having a functional health information system that can be easily used to monitor and control the prevalence of disease is critically important.^[30] Information systems have critical role in helping policymakers and decision makers at all levels, to identify problems, planning, and management to evaluating health services to improve the health of individuals and communities.^[30-33] The Disease Registry is a useful tool for the monitoring of status of health care provision based on the guidelines, development of research, and collection of data at national and international levels.^[34] The data of a registry system are a documented file that systematically collects similar data in order to render scientific services or predetermined policies.^[35] Registries provide information on the natural history of specific disorders and patient data, which are increasingly helpful in evaluation of new treatments and access of patient to costly procedures.^[36] Registry systems allow data to be compared so that, the success rate of ART techniques is well defined.^[37,38] Therefore, the design and implementation of registry systems help the collection and analysis of data; thus policymakers must pay particular attention to the implementation of such systems.^[39]

Conclusions

National registry system helps to better understand the scope and effect of assisted reproduction on the health of infertile couples. A registry is like a national surveillance system for ART. Collecting data on possible outcomes and side effects of ART can help patients to make appropriate decisions about infertility treatment. It helps the experts to provide patients with the optimal care with the best documented treatment methods, and also helps the evaluators to assess public health responses, develop health care policies, and ensure reimbursement of the costs. In general, it helps to better understand the ART and its role and value in helping infertile people and other medical problems.

Although there are ART systems in different countries, there is still no integrated system to compare data from different countries. By designing and implementing an appropriate ART registry system, in addition to collecting and analyzing data,

Table 1: Name, responsible institution, objectives, minimum data set, and voluntary of registries in selected countries

Country	Name of registry	Responsible institute	Objectives of registry	Minimum data set	Voluntary/mandatory
USA ^[17]	National ART Surveillance System (NASS)	CDC and SART	Developing and maintaining the ART standards. NASS is the only data reporting system for ART procedures that has been approved by CDC	Patient demographics, medical history, and infertility diagnoses; clinical information pertaining to the ART procedure type; and information regarding resultant pregnancies and births	Voluntary
Canada ^[18]	The Canadian Assisted Reproductive Technologies Register (CARTR)	The IVF Directors Group of the Canadian Fertility and Andrology Society (CFAS)	Reporting the outcomes of ART cycles which have been done in centers in Canada	Patient demographics, diagnosis, and obstetric history; details of treatment; and pregnancy and birth outcomes for each ART treatment cycle initiated.	Voluntary
Latin American ^[19]	The Latin American Registry of Assisted Reproduction (RLA)	The Latin American Network of Assisted Reproduction (REDLARA)	1-Publishing information about the performed ART procedures 2- Monitoring the results and situation of safety and efficacy 3- Empowering infertile couples to assess the advantages and disadvantages of ART treatments 4- developing an strong database for epidemiological studies	1-Number of treatment cycles per technique and availability 2-Outcome of pregnancies and deliveries	Voluntary
Belgium ^[14]	BELRAP (Belgian Register for Assisted Procreation)	The national College of Physicians for Reproductive Medicine	Facilitating the use and management of the data, providing accurate statistical information on activities and outcome and ensuring the quality control	1-Age 2-Number of embryos transferred and multiple births 3-Outcome according to the number of ET and stage of development at transfer 4-Perinatal outcome and complications 5- PGD/PGS	Voluntary
Denmark ^[20]	The Danish National IVF Registry	the National Board of Health	Monitoring the assisted reproduction. Reporting individual treatment cycles and pregnancy outcomes	An IVF cycle record contains 124 fields such as "Date of birth of the patient", "Labo rank" or "Pregnancy outcome". A non-IVF cycle record contains 46 fields such as "Intrauterine insemination (IUI)", "Ovarian stimulation" or "Date of delivery".	Mandatory
Germany ^[15]	The German IVF Register (Deutsches IVF-Register) D.I.R()	The German Society for Gynecology and Obstetrics	Scientific evaluation of procedures, political decision-making concerning reproductive therapy, the general public, and patients, as well as collecting and publishing the outcomes of IVF and related methods	Demographic data, treatments and complications to treatments and pregnancy, Births per initiated cycles in relation to age and treatment	Voluntary
France ^[12]	The FIVNAT registry (French In Vitro National)	U292 of French National Institute for Health and Medical Research (INSERM)	Collecting information from the beginning of the procedure to the childbirth. Obtaining an extensive knowledge of IVF practice and analyzing facilitating factors	Data regarding frozen embryo replacement (FER) and egg donation (ED) were recorded likewise.	Voluntary

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Table 1: Contd...

Country	Name of registry	Responsible institute	Objectives of registry	Minimum data set	Voluntary/mandatory
Switzerland ^[1,21,22]	FIVNAT-CH Register (National Swiss IVF Register)	The Swiss Society for Reproductive Medicine (SSRM)	Providing scientists with accurate ART data, and also for politicians, media, and patients. Validating the accuracy and the reliability of the collected data	Demographic, Treatments (IVF with ET, GIFT, ICSI, IVF/ICSI, PBD), pregnancy rate, birth rate, miscarriages, ectopic pregnancies, abortions, rate of multiple births, malformations.	Voluntary
Italy ^[23]	Italian National Registry of ART	the Ministry of Health	Collecting and publishing information related to all ART treatments and IUI procedures performed in the country	A 56-item form. Data are collected in three forms: one for the infertility diagnosis and the attempted recovery, one for thawed embryo transfers, and one for obstetric and pediatric data	Mandatory
Egypt ^[16]	Egyptian IVF registry	independent, nonprofit, nongovernmental body	Collecting, analyzing and reporting the effectiveness of treatment schemes and identifying the risk of complications	the medical indications for treatment, the protocol for ovarian stimulation, oocyte collection, details from the laboratory, embryo transfer and luteal support; thawing and replacement of frozen-thawed zygotes and embryos; the pregnancy, delivery, and neonates	Voluntary
SOUTH AFRICAN ^[24]	SOUTH AFRICAN REGISTRY FOR ASSISTED REPRODUCTIVE TECHNIQUES (SARA)	The Southern African Society of Reproductive Medicine & Gynecological Endoscopy (SASREG)	Implementing innovative programs to improve the reproductive care in South Africa, making the assessment to find out if the desired effects have been achieved	Treatments and treatments outcomes. Data collection it is performed separately for IUI procedures and IVF-ICSI-GIFT on different electronic forms. The number of cycles performed for each technique, the number of patients treated, kind of infertility diagnosed, complication during treatments and results, pregnancies outcomes and babies born	Voluntary
Australia and New Zealand ^[25-27]	The Australia and New Zealand Assisted Reproduction Database (ANZARD)	The Fertility Society of Australia and hosted at the National Perinatal Epidemiology and Statistics Unit (NPESU).	Monitoring the perinatal outcomes of assisted reproduction and evaluating the effectiveness of ART treatments	Demographic, cause of infertility, Treatments (IVF, ICSI, FER), follow-up data on pregnancies and deliveries, the outcome of all pregnancies. Complications of ART, pregnancies and deliveries after treatment, congenital anomalies/ chromosomal aberrations in babies born after ART.	Mandatory
Japan ^[28,29]	ART online registry	The Japan Society of Obstetrics and Gynecology (JSOG)	Collecting information on cycles of all ART treatments and Comparing them with the previous years. Reviewing the success and safety of ART in Japan	Procedures and pregnancies by age, transfer cycles and pregnancies (in brackets) by the number of embryos/ blastocysts transferred and age, Pregnancy outcome by age, ongoing pregnancy and delivery, live births, unknown outcome, pregnancy rates, live birth rates	Mandatory

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Table 1: Contd...

Country	Name of registry	Responsible institute	Objectives of registry	Minimum data set	Voluntary/mandatory
India ^[11]	National Art Registry of India (NARI)	the Indian Society of Assisted Reproduction (ISAR)	Providing appropriate help and support for health care providers who deal with infertility problems	Ovarian stimulation, frozen embryo transfer, oocyte donation	Mandatory

the opportunity will be provided to implement new programs to improve fertility management, control and prevention, and also provide quality care for patients. These systems can be used to assess the effectiveness of ART treatments and provide information to policymakers to plan and develop a strong database for epidemiological studies.

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Conflicts of interest

There are no conflicts of interest.

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