

Research Article

Variations in internet self-reporting of infertility success statistics in California infertility practices

MacKenzie Purdy^{1*}, Leslie A. Appiah¹ and John A. Harris²

¹Department of Obstetrics and Gynecology, University of Kentucky Medical Center, 800 Rose Street, Lexington, Kentucky 40536-0293, USA

²Robert Wood Johnson Foundation Clinical Scholars Program, Department of Obstetrics and Gynecology, University of Michigan, 2800 Plymouth Road, Building #10 Room G016, Ann Arbor, Michigan 48109-2800, USA

Abstract

Objective: To compare association of procedure volume and success rates on the publication of infertility success rates on individual infertility provider websites.

Design: Retrospective cohort study

Setting: The internet.

Patients: None.

Interventions: All websites listed on Centers for Disease Control and Prevention website reporting on vitro fertilization were examined for the presence or absence of information on the success rates of the infertility procedures at each practice

Main Outcome Measures: Presence of any information on infertility procedure success rates as a dichotomous variable.

Results: Of the 62 practices listed in the CDC database 34 (55%) of practices (n=34) self-published any infertility success data. 23 (37%) practices listed pregnancy rates and live birth rates per transfer or retrieval, 19 (30%) practices listed pregnancy rate per cycle, and 9 (14%) practices listed live birth rates per cycle. Total number of fresh non-donor cycles performed per year was significantly associated with publication of success rates (odds ratio 2.25 (1.33-3.82) per 100 cycle increase). There was no statistical association with practices with live birth rates per cycle success rates and internet self-reporting of success rates p=.99).

Conclusions: Significant variation in infertility provider's internet self-reporting of success rates is present in this sample. There was statistical association found between total number of fresh non-donor cycles and publication of website success information. Understanding the biases within sources of website information helps educate infertility patients about important and costly treatment decisions.

Introduction

The importance of accessible and accurate publicly available data from in vitro fertilization centers has been discussed over the past two decades [1]. Due to public and legislative concern over the accuracy of data available to the public, two public databases publish IVF success rates, the Center for Disease Control (CDC) and the Society for Assisted Reproductive Technology (SART) [2]. The CDC database was mandated by congress in 1992 after the Fertility Clinic Success Rate and Certification Act was passed to provide outcomes data on every infertility practice performing IVF in the country [3,4]. The SART database is voluntary and has attempted to present information in a more balanced fashion to make it more understandable with the aim of improving patient literacy. Even with these databases, previous work showed that patients are obtaining much of their information about success from IVF facility based websites, not the governmental or professional society websites with some reports noting a 60% acquisition rate [5,6]. The data available on practice websites is not standardized and audited in the ways that CDC and SART datasets are rigorously monitored [7].

Previous studies like Avraham *et al.* [8] examined websites to determine if they follow the AMA criteria for adequate information provided to the consumer. Limited information has been produced

detailing the information provided on individual websites [9]. Since success rates can be presented in pregnancy rate per cycle, per retrieval, or per transfer there can be a large variation in rates reported. The difference occurs due to the fact that more patients are usually participating at the beginning of the cycle compared to the lower number of patients eligible for retrieval and transfer [10,11]. When presenting results per patients beginning a cycle this will cause an increase in the denominator of the equation and therefore lower the percentage of recorded success. If data is presented with the pregnancy rate per transfer then the pregnancy percentage will likely be higher due to a smaller denominator. The equation is then presented as the pregnancy rate as the numerator and number of transfers as denominator. This would also be true when presenting live birth rates per transfer as opposed to cycle or retrieval [12]. Unfortunately, the multiple ways available to report success rates for in vitro fertilization

Correspondence to: MacKenzie Purdy, Department of Obstetrics and Gynecology, University of Kentucky Medical Center, 800 Rose Street, Lexington, Kentucky 40536-0293, USA, Tel: 859-218-1661; **E-mail:** mackenzie.washburn@uky.edu

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may increase variation in success rates and confusion for patients when comparing practices by practice website [13]. It is also important for patients to understand that cycles can be cancelled for multiple reasons including inability to stimulate, inability to tolerate drug therapy, etc. However, these factors are rarely stated during reporting.

The mode of IVF success rate reporting can vary drastically. Little is known about what IVF statistics individual practices publish on their websites, or what factors may predict the publication of these IVF statistics [14,15]. This study attempts to describe the rates of reporting IVF success statistics among California IVF practices and attempts to identify factors that predict if practices are more likely to report these statistics on their website.

Materials and methods

During June and July of 2014, we performed a cross-sectional analysis of all California infertility practice websites registered on the United States Centers for Disease Control (CDC) and Prevention Assisted Reproductive Technology Fertility Clinic Success Rates Report website using a predefined survey instrument. A Google search was performed using the title of the facility and top 20 searches were reviewed. The website that contained the exact name of the facility and identified the provider listed on the CDC website was selected [16]. The website was searched for success rates published and also on whether they listed the URL for the Society for Assisted Reproductive Technology (SART) database or CDC. The SART database was then used to compare results as listed on the provider website. If the website listed successes after 2012 they were unable to be compared secondary to a limited publication from the SART website [17]. The SART website was also used to calculate the total number of cycles completed for that institution in 2012. Each practice was evaluated for the presence and quality of infertility success data present on the website.

Websites were determined to either have a listing of pregnancy success rates or live births or nothing. Those that listed success rates were determined to either specify pregnancy or live birth success rate in reference to the cycle, retrieval, or transfer. Information was also collected on whether the website listed their cancellation rates, their frozen and donor cycle transfer success rates and whether they listed their frequency of multiples. The results were then compared to the SART data from the corresponding year published on the website for any discrepancies.

To better characterize the IVF clinic communities and patients for generalizability, median household income and number of households per city was determined for each IVF clinic. Cause for infertility was broken down based on CDC data with categories including: ovulatory dysfunction, tubal factor, diminished ovarian reserve, male factor, and endometriosis, male and female combinations, other and unknown (Table 1).

This secondary analysis of a de-identified dataset was deemed exempt from review by the University Of Kentucky Office Of Research Integrity.

Statistics: Calculations were then performed using a chi square model comparing facilities that were found to have the highest reported success rates per transfer/retrieval on the SART database. Those in the top quartile of success were analyzed for the amount of reporting to the provider website and calculation was performed with chi square model (Table 2). The amount of cycles performed per facility in 2012 was also determined from the SART database. Those facilities that performed greater than 100 cycles per year were analyzed separately from those

Table 1. Demographic characteristics of California *in-vitro* fertilization (IVF) clinics.

Characteristics	California IVF Clinics	Interquartile Range
Median Household	\$80,180.00	\$61,833-\$94,021
Number of Households per city	221,847	161,198-242,140
Cause for Infertility:		
Ovulatory Dysfunction	5.9%	3.0-7.0%
Tubal Factor	6.7%	3.0-7.0
Diminished Ovarian Reserve	16.5%	7.0-23.0%
Male Factor	16.1%	11.0-19.5%
Endometriosis	3.0%	1.0-5.0%
Female Factor Only	11.0%	7.0-13.0%
Male and Female Factors	18.7%	10.0-27.0%
Other	12.1%	3.0-15.0%
Unknown	9.8%	5.0-15%

Table 2. Unadjusted and adjusted odds ratios for association of website information and total number of fresh non-donor cycles (per 100 cycles).

	Unadjusted	Adjusted
Odds Ratio (95% CI)	2.25 (1.33-3.82)	2.33 (1.31-4.14)

with less than 100 cycles to determine the provider reporting rate on individual websites. An odds ratio was determined for association of website information and total number of fresh non-donor cycles with an adjustment for household income and number of households per city.

We reported the estimated percentage of practices publishing website IVF success statistics in terms of predicted outcome probabilities at the 25th, 50th, and 75th percentile live birth and non-donor cycle performed yearly, holding all other covariates at their observed values, because effect sizes cannot be directly inferred from coefficients of logit models.

Categorical data are presented as numbers and percentages; $P < 0.05$ was considered statistically significant.

Results

62 practices listed in the CDC database were examined. General characteristics, including causes for fertility and SART membership are reported in Table 1. Overall the cities for these clinics are generally large with an average number of households of 221,847 per city (interquartile range (IQR) 161,198-242,140) and have a high median household income of \$80,180 (IQR \$61,833-\$94,021).

55% of practices (n=34) self-published any infertility success data. 37% of practices (n=23) listed pregnancy rates and live birth rates per transfer or retrieval, 30% of practices (n=19) listed pregnancy rate per cycle, and 14% of practices (n=9) listed live birth rates per cycle. 34% (n=21) of facilities listed data from 2012 to present, while the other 39% (n=24) presented data from prior to 2012. 5% of practices listed cancellation rates (n=3). 5% (n=3) of practices listed twin live birth rates with fresh cycles and 6% (n=4) listed triplet live birth rates per fresh cycle.

There is a 2.25 increased odds of publishing in vitro fertilization success rates with each increase of 100 cycles performed per year (95% confidence interval (95% CI) 1.33-3.82). This estimate was stable after

Table 3. Percentage of practices publishing website success information at 25th, 50th, and 75th percentile.

	Estimated Percentage of Practices Publishing Information on Their Website (1) (95% CI)
Total FnD Cycles per Practice at 25 th Percentile (62 cycles)	35.0% (19.0-51.0%)
Total FnD Cycles per Practice at 50 th Percentile (197 cycles)	62.5% (48.3-76.7%)
Total FnD Cycles per Practice at 75 th Percentile (315 cycles)	81.9% (66.8-97.0%)

adjustment for SART membership, median household income, and number of households in the city of the clinic (Table 2). The estimated probability of publishing in vitro fertilization success statistics is 35% at practices at the 25th percentile of total fresh, non-donor cycles yearly compared to 81.9% at the 75th percentile of total fresh, non-donor cycles yearly (Table 3). There was not a statistically significant relationship between the birth rate of fresh non-donor cycles and reporting of in vitro fertilization success rates on a practitioner's website.

Discussion

In California infertility practices, we found that there is a 2.32 increase in the odds of reporting based on increasing cycle number for every 100 cycles done per year. There was no association with the relative success rate of in vitro fertilization and the presence of website success information.

There are several explanations for the association between cycles performed yearly and publication of website information. It is possible that those with larger facilities have greater resources to produce a more informative website. It is also possible that as the number of patients increases the number of requests for transparent publication of success rates also increases, inducing practices to publish this data. Finally, this association could be explained by reverse causation, that is by publishing success rates on the website, this is a competitive advantage and more patients choose this type of practice.

In order for patients to have increased health literacy in relation to IVF treatment it is important to present data that is both correct and understandable. It has been shown that 60% of women are obtaining their information from the Internet, which could be in the form of individual provider websites [4]. If the information is not presented in a standardized fashion or if the results are not explained to the patient there will be misunderstandings and eventually those with unattainable goals [18]. From the data presented on the websites in California it is obvious that there are multiple ways that practitioners are presenting their IVF data.

When examining the websites, 9 listed live births per cycle compared to 22 institutions that listed live births per retrieval or transfer. Presenting data solely by live births per retrieval or transfer can be very confusing for patients due to the fact that it presents the highest percentage possible as opposed to a more realistic percentage that would include live births per cycle [1]. Only 3 websites listed their cancellation rates, which may be important to certain patients to understand before they begin the IVF process. Also only 3 websites listed pregnancy rates of twins and 4 for greater multiples, although this is an important fact to review with patients.

The most obvious limiting factor to this project was size. California does have the largest amount of facilities in the US, listed on the CDC website per state with 62. However, this number is likely not large

enough to fully explore factors within subgroups that may explain provider reporting.

This study helps describe the information to which the infertility patients have access when making important and costly treatment decisions. While there was no statistical association found between self-reporting and increased infertility success rates, there was an association with reporting and the number of infertility procedures performed suggesting increased program transparency with increasing number of cycles. In order for providers to state that patients are informed about IVF at their institution it seems imperative to present data that is legible to the patient and portrays the accuracy of IVF [19,20]. Until we are able to standardize information the onus is on providers to take the initiative to update their data and present it to patients without bias.

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