HHS Public Access

Author manuscript

Epidemiology. Author manuscript; available in PMC 2015 September 01.

Published in final edited form as:

Epidemiology. 2014 September ; 25(5): 773–775. doi:10.1097/EDE.0000000000000153.

Maternal Self-Report of Assisted Reproductive Technology Use in the National Birth Defects Prevention Study: Validation using fertility clinic data

Rebecca F. Liberman[1], **Judy E. Stern**[2], **Barbara Luke**[3], **Jennita Reefhuis**[4], and **Marlene Anderka**[1]

[1]Massachusetts Department of Public Health, Boston, MA

[2]Geisel School of Medicine at Dartmouth, Lebanon, NH

[3]Michigan State University, East Lansing, MI

[4]Centers for Disease Control and Prevention, Atlanta, GA

To the Editor

The use of fertility-enhancing therapies, including assisted reproductive technologies (ART), has more than doubled in the United States between 1996 and 2005.[1] Approximately 1.4% of United States live births and 4.3% of Massachusetts live births are conceived using ART.[2] Several studies have noted an increased risk of birth defects in ART pregnancies compared with spontaneous pregnancies.[3,4]

Previous attempts to validate maternal self-reported ART have shown mixed results. A Danish study demonstrated sensitivity of 83% for assisted conception.[5] However, maternal self-report in the Pregnancy Risk Assessment Monitoring System in the United States overestimated ART use when compared with clinic-reported data.[6]

We compared self-reported ART use among Massachusetts participants in the National Birth Defects Prevention Study (NBDPS) with data from ART clinics. The NBDPS is a population-based, multi-center case-control study of birth defects, with exposure information collected by maternal interview.[3, 7] The Society for Assisted Reproductive Technology (SART) collects ART procedure information from clinics, providing a gold standard for comparison with self-reported information. The SART database contains information from over 91% of ART clinics in the United States, with validation conducted annually.[2] All Massachusetts ART clinics report to SART. SART records have been linked to vital records for Massachusetts deliveries as part of a project to evaluate ART outcomes.[8]

Massachusetts NBDPS participants with in-state deliveries between September 2004 and December 2008 were matched to SART records by delivery date, birth/fetal death certificate number, and birth outcome. Sensitivity and specificity were calculated to measure accuracy

Address correspondence to: Rebecca Liberman, Center for Birth Defects Research and Prevention, Massachusetts Department of Public Health, 250 Washington Street, 5th Floor, Boston, MA 02108, Phone: 617-624-5503; FAX: 617-624-5574, rebecca.liberman@state.ma.us.

of self-reported ART use among NBDPS participants compared with use recorded in SART. Variables compared include in-vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI), use of donor eggs, frozen eggs or embryos (frozen cycle), and presence of multiple fetuses on ultrasound. The NBDPS did not collect ICSI information until 2006, so these analyses are restricted to 2006-2008 deliveries.

Of 1,452 Massachusetts NBDPS participants with in-state deliveries during the study period, 77 (5.3%) matched to a record in the SART database. Four NBDPS subjects who reported IVF or ICSI did not match to a SART record, possibly because of misreporting or because ART had been performed out-of-state.

Among NBDPS subjects who matched to SART records, specificity was 87% or greater for all procedures and outcomes examined. Sensitivity was 91% for IVF use and did not differ by case-control status. Sensitivity was 100% for use of frozen cycle and presence of multiple fetuses. Sensitivity was lower for ICSI (71%) and donor egg use (67%), although the number of donor egg cycles was small. Sensitivity for ICSI use was 82% among 20 subjects interviewed at less than 9 months following delivery, compared with 60% among 24 subjects interviewed at 9 months or more. ICSI sensitivity was 80% among 37 cases vs. 50% among 7 controls (data not shown).

To our knowledge, this is the first study to validate maternal ART exposure information in the NBDPS. The study's main strength is its use of validated ART clinic data, providing a gold-standard for comparison with maternal self-report. Limitations include small numbers for several ART procedures and within subgroups. Also, we could evaluate only Massachusetts residents. However, although Massachusetts residents comprise only 12% of NBDPS subjects, they account for roughly 40% of all study subjects who report a fertility procedure.

Among deliveries to NBDPS subjects who matched to SART records, self-reported use of IVF and several other ART procedures and outcomes demonstrated good agreement with clinic data, while use of ICSI and donor eggs was underreported. Future studies need to validate ART exposure with larger sample sizes, including subjects from other states. These results increase confidence in observed associations between ART and birth defects[3] in the NBDPS.

Acknowledgments

We acknowledge Daksha Gopal for her assistance with this project.

Conflicts of Interest and Sources of Funding: Rebecca Liberman and Marlene Anderka work in a department that has received funding from the Centers for Disease Control and Prevention to participate in the National Birth Defects Prevention Study. Jennita Reefhuis works at the Centers for Disease Control and Prevention and is a co-investigator for the National Birth Defects Prevention Study. Barbara Luke is a consultant to the Society for Assisted Reproductive Technology, and both Barbara Luke and Judy Stern have received grant funding from the National Institutes of Health.

This work was supported in part by the Centers for Disease Control and Prevention, Grant #1U01DD000493.

References

1. Wright VC, Chang J, Jeng G, Macaluso M. Assisted reproductive technology surveillance--United States, 2005. MMWR Surveill Summ. 2008; 57(5):1–23. [PubMed: 18566567]
2. Sunderam S, Kissin DM, Flowers L, Anderson JE, Folger SG, Jamieson DJ, et al. Assisted reproductive technology surveillance--United States, 2009. MMWR Surveill Summ. 2012; 61(7):1–23. [PubMed: 23114281]
3. Reefhuis J, Honein MA, Schieve LA, Correa A, Hobbs CA, Rasmussen SA. Assisted reproductive technology and major structural birth defects in the United States. Hum Reprod. 2009; 24(2):360–366. [PubMed: 19010807]
4. Davies MJ, Moore VM, Willson KJ, Van Essen P, Priest K, Scott H, et al. Reproductive technologies and the risk of birth defects. N Engl J Med. 2012; 366(19):1803–1813. [PubMed: 22559061]
5. Hvidtjorn D, Grove J, Schendel D, Schieve LA, Ernst E, Olsen J, et al. Validation of self-reported data on assisted conception in The Danish National Birth Cohort. Hum Reprod. 2009; 24(9):2332–2340. [PubMed: 19454590]
6. Barradas DT, Barfield WD, Wright V, D'Angelo D, Manning SE, Schieve LA. Assessment of assisted reproductive technology use questions: Pregnancy Risk Assessment Monitoring System Survey, 2004. Public Health Rep. 2012; 127(5):516–523. [PubMed: 22942469]
7. Yoon PW, Rasmussen SA, Lynberg MC, Moore CA, Anderka M, Carmichael SL, et al. The National Birth Defects Prevention Study. Public Health Rep. 2001; 116(Suppl 1):32–40. [PubMed: 11889273]
8. Declercq ER, Belanoff C, Diop H, Gopal D, Hornstein MD, Kotelchuck M, et al. Identifying women with indicators of subfertility in a statewide population database: operationalizing the missing link in assisted reproductive technology research. Fertil Steril. 2014; 101(2):463–471. [PubMed: 24289994]

Table

Sensitivity and Specificity of Maternal Self-Reported ART Use Among Massachusetts NBDPS Participants Compared with Clinic Data from SART[a]

		SART			
ART Use	**NBDPS**	**Yes**	**No**	**Sensitivity (95% CI) (%)**	**Specificity (95% CI) (%)**
IVF	**Yes**	69	0	91 (82 to 96)	N/A
	No	7	0		
ICSI[b]	**Yes**	15	3	71 (48 to 89)	87 (66 to 97)
	No	6	20		
Donor Egg[c]	**Yes**	4	0	67 (22 to 96)	100 (95 to 100)
	No	2	70		
Frozen cycle[c]	**Yes**	4	1	100 (40 to 100)	99 (92 to 100)
	No	0	71		
Multiple Fetuses	**Yes**	41	2	100 (91 to 100)	94 (81 to 99)
	No	0	34		

CI denotes confidence interval.

[a] Among 77 NBDPS subjects who matched to SART. 1 subject reported “Don't Know” for fertility procedure and was excluded. This subject was recorded in SART as having had IVF and ICSI.

[b] Based on 46 NBDPS subjects who delivered between 2006 and 2008 and matched to SART. 2 subjects were missing ICSI information in SART and were therefore excluded from this analysis.

[c] 1 NBDPS subject reported “Don't Know” for fertility procedure and was excluded. This subject was recorded in SART as having had no donor egg or frozen cycle.

NOTE: 1 NBDPS subject who reported IVF and 3 subjects who reported ICSI did not match to SART. If all 4 of these unmatched subjects had IVF, sensitivity would be 91% (95% CI = 83% to 96%). If none of these subjects had IVF, sensitivity would be 90% (95% CI = 81% to 96%).

If all 3 unmatched subjects who reported ICSI actually had the procedure, ICSI sensitivity would be 75% (95% CI = 53% to 90%). If none of these 3 subjects had the procedure, ICSI sensitivity would be 67% (95% CI = 41% to 87%).