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Are prior pregnancy outcomes relevant for models of fertility-specific distress or infertility helpseeking?

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Abstract

Women with prior pregnancy but no live birth are inconsistently termed as either 'primary infertile' or 'secondary infertile' in psychosocial studies of infertile women. The goal of this study was to discover whether infertile women who had experienced pregnancies but no live births were more similar in attitudes and behavior to infertile women who had not experienced pregnancies or to those who had live births. We used the *National Survey of Fertility Barriers (NSFB)*, which contains self-reported data from a probability-based sample of US women aged between 25 and 45, to accomplish our goal. In this cross-sectional analysis, infertile women who had not experienced pregnancies were compared on the basis of fertility-specific distress (FSD) and medical help-seeking for infertility to women who had had pregnancies with live births and women with pregnancies but no live births. Women were interviewed by telephone in their homes. Data of 1,027 women who had had an infertility episode within the past 10 years were analyzed using multiple regression and logistic regression. Infertile women who had never been pregnant experience higher levels of FSD and were more likely to seek treatment than infertile women who had been pregnant, regardless of the outcome of the pregnancy.

Keywords: *Infertility, treatment choice*

Introduction

Medical practitioners and reproductive epidemiologists categorise women as infertile if they experience a year of unprotected intercourse without conception (Zegers-Hochschild et al., 2009). Medical definitions typically further distinguish between primary and secondary infertility. Some research makes the primary/secondary distinction based on conceiving versus not conceiving prior to experiencing infertility (Downey & McKinney, 1992; Larsen, 2000; Vahidi et al., 2009); other research makes the primary/secondary distinction based on the birth of a child (Epstein & Rosenberg,

2005; Nene et al., 2005; Awartani et al., 2009). In this article, we examine the effects of different primary/secondary distinctions on fertility-specific distress (FSD) and infertility help-seeking among a probability-based sample of US women of reproductive age. We seek to refine further the psychosocial definition of infertility by comparing three categories of women: (1) those who have never conceived, (2) those who have conceived but not had a live birth and (3) those who have had a live birth, but later experienced infertility. Our key purpose in doing so is to examine how the terms 'primary infertility' and 'secondary infertility' might be most productively used in studies of psychosocial aspects of infertility.

Many people associate infertility with involuntary childlessness, but experiencing infertility after having at least one child is quite common (Larsen, 2000; Chandra & Stephen, 2006). We know of no studies, however, that have investigated whether women with children, or women with prior pregnancies but no children and subsequent infertility differ from women who are involuntarily childless with regard to distress levels and patterns of help-seeking.

Any attempt to understand differences in the experience and behavior of women with primary and secondary infertility is complicated by confusion about what the terms 'primary infertility' and 'secondary infertility' actually mean. Medical dictionaries define secondary infertility as 'infertility in a patient who has previously conceived' (Anderson, 2003, p. 923), and most clinicians and reproductive endocrinologists accept this definition. Some researchers of psychosocial implications of infertility have followed their lead (Downey & McKinney, 1992; Larsen, 2000; Vahidi et al., 2009). Other researchers (Epstein & Rosenberg, 2005; Nene et al., 2005; Awartani et al., 2009) define secondary infertility as infertility in a woman who has had at least one previous child.

Still others (Ozkan & Baysal, 2006; Upkong, 2006; McCarthy, 2008) use the terms 'primary infertility' and 'secondary infertility' without defining these terms operationally. The confusion between alternative definitions is evident in this excerpt found on the web site of the World Health Organization (2010): 'Primary infertility is infertility in a couple who have never had a previous child. Secondary infertility is failure to conceive following a previous pregnancy.'

Some researchers have abandoned the distinction between 'primary infertility' and 'secondary infertility' (Benyamini et al., 2005; Domar et al., 2010; Mahajan et al., 2010). A few researchers have avoided distinguishing between 'primary infertility' and 'secondary' infertility by limiting their samples to those with no children (Pasch et al., 2002; Mindes et al., 2003), but they do not report whether the women have had pregnancies (e.g. pregnancies that ended in miscarriage, stillbirth, or abortion). Because not all pregnancies result in a live birth, some women would be classified as having primary infertility by one definitional strategy and as having secondary infertility by the other.

How should psychosocial research distinguish between primary and secondary infertility: having had a pregnancy or having had a live birth? If failure to achieve motherhood is the source of infertility distress, childless infertile women should have higher levels of distress than women who have children and then experience infertility. The primary/secondary distinction could therefore be classified on the basis of childlessness. Infertile women who have been pregnant, however, may be more hopeful about their fertility and, therefore, exhibit lower levels of distress than infertile women who have never been pregnant. Likewise, although it is plausible that all childless infertile women will be more likely to pursue treatment than infertile women who already have a child, women who have previously conceived – even though they have not had a live birth – may be more confident in their ability to conceive again and may therefore be less likely than infertile women who have never conceived to pursue treatment. These latter two possibilities suggest that the primary/secondary distinction could be made on the basis of conception. Thus, we ask whether infertile women with a pregnancy but *no live births* respond more like never-pregnant infertile women, more like women who experience infertility after the birth of a child, or according to some other pattern. In this article, we test three hypotheses:

H1: Women who have never conceived will have different levels of FSD and will engage in different levels of help-seeking than women experiencing infertility after a live birth, controlling for demographic characteristics.

H2: Women who have never conceived will have different levels of FSD and will engage in different levels of help-seeking than women experiencing infertility after conception without a live birth, controlling for demographic characteristics.

H3: Women who have conceived but had no live births will have different levels of FSD and will engage in different levels of help-seeking than women who experience infertility after a live birth, controlling for demographic characteristics.

Materials and Methods

Sample

The data come from the *National Survey of Fertility Barriers (NSFB)*, a national random-digit-dialing telephone survey we designed to assess social and health factors related to reproductive choices and fertility for US women (Johnson et al., 2009). The first wave of the NSFB was collected between September 2004 and December 2007 and interviewed 4,787 women aged between 25 and 45 in the US. We draw our data for this article from 1,027 women in this sample who reported experiencing an episode of infertility in the past 10 years. Sampling procedures and selection criteria for the NSFB were such that the sample would adequately represent women from racial/ethnic minority groups, women who have experienced infertility and women who desire more children. The response rate to the screener was 53.7%. This response rate reflects the declines experienced in recent telephone surveys (McCarty et al., 2006). The characteristics of our sample, however, are similar to findings from the National Survey of Family Growth (NSFG), an in-person survey with higher response rates. We therefore have confidence in the representativeness of our sample. Additional details about the sampling strategy are available in Johnson et al. (2009). We exclude a few cases who selected 'some other race' because they were too heterogeneous to analyze as a group.

Concepts and measures

Infertility type is the focal independent variable for this project. Participants were classified as infertile if they answered yes to the question, 'Was there ever a time when you were *trying* to get pregnant but did not conceive within 12 months?' or they reported trying for more than 12 months to conceive a specific pregnancy. Next, *no pregnancy, no live birth* and *live birth* were constructed from detailed birth and pregnancy histories. Women were classified as having *no pregnancy* if they had never been pregnant at the time of their infertility episode. Women were classified as *no live birth* if they had no children but a pregnancy that ended in a stillbirth or an abortion (spontaneous or induced). In analyses not presented in this article, we re-ran the regressions with induced abortion as a separate predictor and our results did not change. Women were classified as having a *live birth* if they had had at least one live birth prior to the infertility episode. Of the infertile women in our sample, 159 (14.8%) reported experiencing at least two infertility episodes. These women were classified according to their status at the time of the first infertility episode.

Dependent variables. One of the two dependent variables in this analysis is FSD. A measure of FSD was developed because general measures of distress are unlikely to be sufficiently sensitive or specific to the problems of infertility to reflect the experience of many women adequately (Jacob et al., 2007; Schmidt, 2009). It was important for the purposes of the larger study to phrase questions in language general enough to apply to other fertility barriers in addition to infertility (such as pregnancy loss and situational fertility barriers). In addition, it was necessary for us to construct a short measure in order to ease respondent burden and allow time to ask all of the other questions included in the survey. Thus, rather than use the longer scales that have already been developed, we created a six-item scale comprised of questions that draw on that Infertility Reaction Scale of Hjelmstedt et al. (1999), qualitative research on infertile couples (e.g. Greil, 1991) and the clinical experience of members of the research team. Respondents were presented with a series of items and asked whether they felt this way frequently, occasionally, seldom or never. The items were as follows: I felt cheated by life; I felt that I was being punished; I felt angry at God; I felt inadequate; I felt seriously depressed about it and I felt like a failure as a woman. The scale was computed using the mean of available items and then re-scaled so that it ranged from 0 to 1. Higher scores indicate greater distress. This scale has a Cronbach's alpha of 0.771 for the sample used in this analysis.

The other dependent variables in this analysis involve infertility help-seeking, which measures the extent to which women have pursued treatment. Respondents were asked a series of questions about help-seeking, tests and treatments. From these, we constructed three binary variables: (1) *talked to a doctor about infertility*; (2) *had tests for infertility* and (3) *had treatment for infertility*. The variables are constructed so that anyone at a higher value has satisfied the conditions for all lower values. For example, anyone who has had tests has also talked to a doctor. The reference category for each variable includes all women who have not reached that step in the help-seeking process. For example, women who have not talked to a doctor as well as women who have talked to a doctor but not had tests are assigned a value of '0' for the 'had tests' variable.

We included demographic variables that could account for differences in the associations between the three infertility categories and FSD or help-seeking. *Race/ethnicity* is based on the two standard Census questions about race and Hispanic ethnicity (U.S. Census Bureau, 2008). Respondents could choose more than one race category. Therefore, individuals who reported more than one category were classified according to coding rules that gave first priority to identification as 'Hispanic' and second priority to identification as 'Black.' We classified respondents as White, Black, Hispanic or Asian. *Age* and *education* were measured in years. Because it is possible that deliberately delaying child-rearing

may affect FSD, and help-seeking behavior, we constructed a variable to measure the age at which each respondent indicated that she was open to becoming pregnant. We have data for each pregnancy and for each period of regular unprotected intercourse lasting 12 months or more indicating whether the respondent was trying to become pregnant, trying not to become pregnant or 'OK either way' at that time. *Age at first OK* is a quantitative variable indicating the first age at which a respondent said she was either trying to become pregnant or OK either way. *Economic hardship* is a unidimensional scale ($\alpha = 0.82$), based on three questions asking respondents if they had trouble in the past year paying bills, affording needed items or obtaining health care. All continuous variables were mean-centered before being included in the multivariate analyses. Using the software developed by Soper (2011), we conducted a power analysis and determined that, with eight independent variables, 1,027 cases provide us with ample power to detect an effect as small as 0.05.

Analytic strategy

We first analyze bivariate associations between infertility type and characteristics of women in the sample. For categorical variables, we used chi-square tests to assess significant differences between groups. For continuous variables, we used one-way analysis of variance (ANOVA) with Tukey *post hoc* tests for specific group comparisons. We then conducted ordinary least squares (OLS) multiple regressions to assess the relationship between infertility type and FSD, adding indicators of fertility type first and then controlling for other characteristics. Our other dependent variables, 'talked to a doctor', 'had tests', and 'had treatment' are binary; therefore, we use binary logistic regression (Long & Freese, 2006). We used the same strategy for entering blocks of independent variables as was used for the analysis of FSD.

Results

Table I displays the descriptive statistics for the sample showing similarities and differences between infertile women with no pregnancies prior to their first infertility episode, those who had been pregnant but had no live births and those who had given birth before the infertility episode. There were a number of statistically significant differences among the three groups of women. Looking first at categorical variables, a considerably higher proportion of women with no prior pregnancies sought infertility treatment than women in either of the other categories. They were more likely to talk to a doctor about infertility (64.2% compared to 28.9% and 25.6%), to have tests (54.4% compared to 17.8% and 17.8%) and to receive treatment for infertility (36.6% compared to 4.4% and 10.8%). 'No pregnancy' is less common

Table I. Descriptives by no pregnancy/ no live birth/ live birth.

Categorical variables	No pregnancy (n = 399)		Pregnancy-no live birth (n = 45)		Pregnancy live birth (n = 583)		p	
<i>Helpseeking</i>								
Talked to a doctor	64.2%		28.9%		25.6%		***	
Had tests	54.4%		17.8%		17.8%		***	
Had treatment	36.8%		4.4%		10.8%		***	
<i>Race</i>								
White	59.1%		44.4%		47.7%		**	
Black	19.5%		33.3%		28.1%		**	
Hispanic	17.3%		20.0%		22.0%		n.s	
Asian	4.0%		2.2%		2.2%		n.s	
<i>Continuous variables</i>								
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	<i>p</i>	
Fertility-specific distress	0.41	0.30	0.29	0.28	0.25	0.25	***	1 vs 2,3
Age (25–45)	33.78	5.28	33.38	5.22	33.56	5.47	n.s	
Age at first ok	28.44	5.08	25.25	5.35	25.04	5.15	***	1 vs 2,3
Education (years)	15.26	2.88	14.70	2.35	14.07	2.65	***	1 vs 3
Economic hardship	1.53	0.77	1.86	0.84	1.69	0.77	**	1 vs 3

Chi-square performed for categorical variables, ANOVA with Tukey *post hoc*s for continuous variables.*p < 0.05; **p < 0.01; ***p < 0.001.

Table II. Multiple regression analysis of fertility specific distress by various independent variables and no pregnancy/no live birth/live birth.†

Independent variables	Model 1				Model 2			
	B	S.E.	β	p	B	S.E.	β	p
No pregnancy	0.14	0.02	0.25	***	0.14	0.02	0.24	***
Pregnancy, no live birth	0.02	0.05	0.01	n.s.	0.02	0.05	0.01	n.s.
Black					-0.02	0.02	-0.03	n.s.
Hispanic					-0.06	0.03	-0.08	n.s.
Asian					-0.02	0.05	-0.01	n.s.
Age					0.00	0.00	0.05	***
Age at first ok					0.00	0.00	0.05	n.s.
Education					0.00	0.00	-0.02	n.s.
Hardship					0.02	0.01	0.06	n.s.
R squared	0.062				0.079			

*p < 0.05; **p < 0.01; ***p < 0.001.†'Live birth' is the reference category.

among Black and Hispanic women than it is among White and Asian women. There were also differences by pregnancy status among the continuous variables. Women with no prior pregnancies had higher FSD (0.41) than women in the other two categories (0.29 and 0.25). Women with no prior pregnancies were somewhat older (28.44) than women in the other two groups (25.25 and 25.04) at the first time in their life when they were trying to become pregnant or okay with becoming pregnant. Educational attainment is lower among women who have had a live birth than among women who have never been pregnant. Women who have never been pregnant have lower levels of economic hardship than women who have had a live birth.

Table II displays the results of the OLS multiple regression of FSD on infertility type. Model 1 replicates the bivariate associations between infertility type and FSD. The reference category is women who have had a live birth. Women with a prior pregnancy but no live birth did not have significantly different distress scores than the live birth group, although women without a prior pregnancy had significantly higher distress scores than women who have had a live birth

($\beta = 0.26$). Supplemental analyses (not shown) using women with no pregnancies as the reference category show that women with no live births are significantly different from women with no pregnancies on FSD, suggesting that the primary/secondary distinction here is *conception, not birth*. This model accounts for approximately 6.2% of the variation in FSD ($R^2 = 0.062$). This relationship persists when demographic characteristics are controlled in the final model ($\beta = 0.24$; $R^2 = 0.079$), suggesting that it is not an artefact of other characteristics of women in the different groups.

Table III displays the binary logistic regression results for the medical help-seeking variables. The first two models show the results for 'talked to a doctor' as the dependent variable. Model 1 shows that a prior pregnancy with no live birth does not differ from a prior pregnancy with a live birth with regard to the odds of talking to a doctor, but that no prior pregnancy is associated with much higher odds of talking to a doctor. Compared to women who have had a child (the omitted category), the odds of talking to a doctor are over five times higher for women with no pregnancies (OR = 5.19). Those who have had a pregnancy but no live birth

Table III. Binary logistic regression of treatment-seeking by various independent variables and no pregnancy/no live birth/live birth.†

Independent Variables	Talked to a doctor						Had tests						Had treatment																	
	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6		Model 5		Model 6															
	B	SE	OR	p	B	SE	OR	p	B	SE	OR	p	B	SE	OR	p														
No pregnancy	1.65	0.14	5.19	***	1.53	0.17	4.61	***	1.48	0.18	4.39	***	1.55	.17	4.71	***	1.39	0.20	4.00	***										
Pregnancy, no live birth	0.19	0.34	1.21	n.s.	0.27	0.42	1.31	n.s.	0.09	0.48	1.09	n.s.	-0.20	0.54	0.82	n.s.	-0.16	0.63	0.85	n.s.										
Black					-0.66	0.20	0.52	**	-0.54	0.21	0.58	**					-0.69	0.24	0.50	**										
Hispanic					-0.66	0.21	0.51	**	-0.72	0.23	0.49	**					-0.72	0.26	0.49	**										
Asian					0.02	0.42	1.02	n.s.	0.37	0.42	1.45	n.s.					-0.10	0.44	0.90	n.s.										
Age					0.02	0.02	1.02	n.s.	0.03	0.02	1.04	n.s.					0.05	0.02	1.05	n.s.										
Age at first ok					0.03	0.02	1.03	n.s.	0.02	0.02	1.02	n.s.					0.00	0.03	1.00	n.s.										
Education					0.01	0.03	1.01	n.s.	0.05	0.03	1.05	n.s.					0.07	0.04	1.07	*										
Hardship					-0.26	0.11	0.77	*	-0.280.12	0.75	*						-0.19	0.14	0.83	n.s.										
McKelvey & Zavoina's R squared	0.162						0.171						0.255						0.151						0.266					

* p < 0.05 ; ** p < 0.01 ; *** p < 0.001 .

†'Live birth' is the reference category.

do not differ significantly from those who have had a live birth. These associations persist when controls are added in Model 2; the odds of seeking medical help are still much greater for women who have never been pregnant compared to infertile women who have had a live birth (OR = 4.61). As with FSD, the primary/ secondary distinction is *conception* rather than *live birth*.

Models 3 and 4 display results for 'had tests' as the dependent variable. As was the case for talking to a doctor, compared to women who have had a child, the odds of having had tests are over five times higher for women with no pregnancies (OR = 5.19). Again, those who have had a pregnancy but no live birth do not differ significantly from those who have had a live birth. The odds of having tests remain much greater for women who have never been pregnant than the odds are for infertile women who have had a live birth (OR = 4.39) once controls are added in Model 4. The final two models show results with 'had treatment' as the dependent variable. Model 5 shows that, compared to women who have had a child, the odds of having treatment are almost five times higher for women with no pregnancies (OR = 4.71). Again, those who have had a pregnancy but no live birth do not differ significantly from those who have had a live birth. Furthermore, Model 6 shows that the odds of having treatment are still much greater for women who have never been pregnant than they are for infertile women who have had a live birth controlling for other variables (OR = 4.00). For treatment, as with FSD, the primary/secondary distinction is *conception* rather than *live birth*.

In each analysis, McKelvey & Zavoina's R² increases from the first model (0.162, 0.171, and 0.151, respectively) to the second model 2 (0.242, 0.255, and 0.266, respectively), showing that the control variables are associated with medical help-seeking even though they do not explain the association between pregnancy type and help-seeking.

Discussion

Our results support the hypothesis that women who have never conceived differ from women who have conceived, regardless of the outcome. The results fail to support the hypothesis that women who have conceived but have not had a live birth experience different levels of FSD and help-seeking than women with a live birth. These results remain when controls are added. Thus, evidence from this large random sample suggests that primary infertility should be defined as infertility with no pregnancies and secondary infertility should be defined as infertility among women who have had pregnancies, regardless of the outcome of the pregnancy.

This study supports what many clinicians and researchers know – that there is considerable variability in the experience of infertility (Benyamini et al., 2005). We interpret our findings as suggesting that *conception*, even when it does not result in a live birth, qualitatively changes the experience of infertility. We suspect that women who have had a pregnancy, even without a live birth, are more likely to think that

they can conceive again. This confidence in one's ability to conceive without medical assistance might well lead both to lower distress rates and to a lower likelihood of help-seeking.

As with all studies, there are limitations to the data. First, our data are cross sectional. We therefore cannot firmly establish causal connections. The outcome variables, however, clearly come after prior pregnancy status in time. Another drawback is that our data focuses on current FSD, not on distress at the time of the infertility episode. It is likely that women who experienced their episode further in the past will have different distress than women who are closer to their episode. For example, women who had no pregnancies at the time of the infertility episode but have had subsequent live births should have less FSD now than in the past. In general, however, this would result in lessening differences between the different groups of women; therefore, we have confidence in our assertion that infertility without a prior pregnancy is considerably more distressing than infertility after a pregnancy.

Our analysis distinguished by considering three infertility types instead of the usual two. By doing so, we were able to demonstrate that the infertile women who have had a prior pregnancy but no live birth resemble women who had live births, more than they resemble never-pregnant infertile women. Thus, psychosocial research on infertility should consider prior pregnancy as an indicator of secondary infertility, as opposed to treating having a child as the distinguishing factor. Additionally, therapists working with infertile patients should consider prior pregnancies in addition to parental status when counselling infertile women concerning infertility. Our work provides counsellors and other clinicians with more accurate information about how prior pregnancies affect women's experiences of infertility.

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