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Arthur L. Greil
Alfred University

Karina M. Shreffler
Oklahoma State University

Lone Schmidt
University of Copenhagen

Julia McQuillan
University of Nebraska-Lincoln, jmcquillan2@Unl.edu

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Variation in distress among women with infertility: evidence from a population-based sample[†]

Arthur L. Greil^{1*}, Karina M. Shreffler², Lone Schmidt³, Julia McQuillan⁴

1. *Department of Sociology, Alfred University, 1 Saxon Drive, Alfred, NY 14802, USA*

2. *Human Development and Family Science, Oklahoma State University, Tulsa, OK, USA*

3. *Social Medicine, University of Copenhagen, Copenhagen, Denmark*

4. *Department of Sociology, The University of Nebraska at Lincoln, Lincoln, NE, USA*

*. Correspondence address. Tel: +1-607-871-2885; Fax: +1-607-871-2085; E-mail: fgreil@alfred.edu

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Abstract

BACKGROUND

We examine variation in fertility-specific distress (FSD) and

general distress according to different experiences of infertility among 1027 US women who have experienced infertility within the previous 10 years.

METHODS

General distress was measured by a short form of the Center for Epidemiological Studies-Depression. Multiple regression analysis was conducted on self-report data (based on a telephone interview) from a probability-based sample of US women aged 25–45 years. We compare women with infertility who have had a prior pregnancy (secondary infertility, $n = 628$) to women with infertility with no prior pregnancies (primary infertility, $n = 399$). We further distinguish between women with infertility who were actually ‘trying’ to become pregnant (the infertile with intent) with those who met the medical definition of infertile but did not describe themselves as trying to become pregnant (infertile without intent).

RESULTS

Both types of infertility (primary versus secondary) ($\beta = 0.31^*$) and intentionality (infertile with and without intent) ($\beta = 0.08^*$) are associated with FSD. These associations persist when we control for resource and demographic variables, life course variables, social support and social pressure variables. General distress does not vary by infertility type or intentionality.

CONCLUSIONS

Results reveal variation in women's recalled experiences of infertility and that FSD is more sensitive to effects of different experiences than general distress. Women with primary infertility who were explicitly trying to become pregnant at the time of the infertility episode stand out as a particularly distressed group. Caregivers should be aware that the emotional needs of women with primary infertility may differ from those with secondary

infertility.

Introduction

Although there are many studies of psychological distress among women with infertility (for reviews see [Henning and Strauss, 2002](#); [Greil et al., 2010](#)), only a handful of studies have examined the relationship between infertility and psychological distress among women who have not sought medical help for infertility. Furthermore, many studies have treated women with infertility as a monolithic group, thus missing important distinctions among women with different types of infertility (primary or secondary) or degree of ‘intentionality’ at the time of the infertility episode (trying, or open to conception). We examine variations in fertility-specific distress (FSD) and general distress (CESD) by type of infertility in a nation-wide probability sample of 4796 US women, of which 1027 have reported at least one episode of infertility within the past 10 years. We compare women with infertility who have had a prior pregnancy (secondary infertility) to women with infertility with no prior pregnancies (primary infertility). In addition, we compare women who were actually ‘trying’ to become pregnant at the time of their infertility episode (the infertile with intent) with those who met the medical definition of infertility but were not explicitly trying to become pregnant (the infertile without intent). Because characteristics such as race, income, access to private health insurance, importance of motherhood and treatment-seeking differ by type of infertility, we explore whether controlling for various characteristics explains the associations between type of infertility, intentionality and distress. In addition, we assess whether or not measures of FSD or measures of general distress are more sensitive to variations in the experience of infertility.

Infertility and psychological distress

According to commonly accepted medical criteria for infertility, women are categorized as infertile if they experience a year or more of unprotected intercourse without conception ([Zegers-Hochschild et al., 2009](#)). Using this definition, the National Survey of Family Growth estimates that 7.4% of married US women were currently infertile in 2002 ([Chandra and Stephen, 2006](#)). Tests of the hypothesis that infertility is a source of psychological distress have typically used standardized measures normed on the general population to see if the infertile score is different than the population at large or if they have higher scores than women in a non-infertile comparison group. Most studies employing standardized measures of general psychological distress have found that women with infertility score as more distressed than persons with no reported fertility problems on at least some subscales, but less distressed than those with clinical mental illnesses ([Greil, 1997](#); [Fekkes et al., 2003](#); [Monga et al., 2004](#)).

Drawing conclusions from research on infertility and distress is made more difficult by several methodological limitations in prior studies. First, women with infertility who serve as subjects for much research on infertility and psychological distress do not always represent the full range of women who meet the criteria for infertility. Until recently, most studies on the psychosocial consequences of infertility were limited to clinic-based samples of women-seeking treatment. In the USA, it is estimated that only half of couples with infertility seek treatment ([Chandra and Stephen, 2010](#)). Therefore studies based on clinic samples capture the experiences of only one-half of women with infertility. Because non-treatment seekers differ substantially from treatment seekers on race, socioeconomic status and other characteristics, this is a potentially serious omission ([Greil et al.,](#)

[2010](#)). In addition, the use of clinic samples confounds the consequences of treatment seeking, treatment itself and fertility status. Evidence suggests that the common characterization of infertile woman as totally immersed in the process of trying to become pregnant describes only treatment seekers, and does not reflect the broader experience of non-treatment seekers ([Greil and McQuillan, 2004](#)).

Fertility-specific distress

A second reason for concern about findings regarding the psychological sequelae of infertility is the types of measures used to capture psychological distress. Conventional general measures of distress are unlikely to be sufficiently sensitive or specific to the problems of infertility to adequately reflect the experience of many women ([Jacob et al., 2007](#); [Schmidt, 2009](#)). Specific measures of infertility distress tend to have strong correlations with standardized measures of distress, indicating the face validity of fertility-specific measures ([Ulbrich et al., 1990](#); [Abbey et al., 1992](#)). Fertility-specific measures, however, do not permit comparison with control groups or population norms. Thus, these measures are most useful for comparisons among women and couples with infertility.

A third reason for concerns about findings in studies of the psychological consequences of infertility among women is the heterogeneity among women with infertility. For example, [Wischmann et al. \(2001\)](#) found that most women and couples with infertility do not have psychopathology, but there are some who need psychological help. Much of the research on variation in distress among women with infertility has focused on differences in coping strategies and other psychological attributes ([Benyamini et al., 2005](#); [Miles et al., 2009](#); [Peterson et al., 2009](#); [Sexton et al., 2010](#); [Van den Broeck et al., 2010](#)). Much less research has looked at

differences by type of infertility or demographic, situational and attitudinal correlates of infertility distress.

Variables influencing distress among women with infertility

Among women with infertility, several characteristics are associated with differing levels of distress. FSD measures are particularly well-suited for assessing variation among women with infertility, although few measures of FSD have been utilized for this purpose. [Greil and McQuillan \(2004\)](#) have divided women with infertility into the ‘infertile with intent’ (women who say they tried to conceive for at least 12 months without conception) and the ‘infertile without intent’ (women who report having had unprotected intercourse without conception but who do not say that they were explicitly trying to conceive at the time) and have found these two groups to be different in striking ways. It is important to point out that this ‘intent’ measure is not a measure of the general desire for a child but rather a measure of planfulness. Many women in the USA say that they are neither planning to become pregnant or planning not to become pregnant but rather are ‘okay either way’ ([McQuillan et al., 2010](#)). Many of these women may welcome a pregnancy when it occurs and many may become concerned about their fertility should they fail to become pregnant over time.

Intentionality with regard either to a particular pregnancy or pregnancy in general and wanting a(nother) child are two conceptually separate variables, and the nature of their relationship to one another is an empirical question. Although infertile women without intent are less likely to pursue treatment ([Greil et al., 2009](#)), some of them do seek treatment. Women who are infertile with intent do not differ from the infertile without intent with regard to general distress, but they do score significantly higher on FSD ([Greil and McQuillan, 2010](#)).

Many people associate infertility with involuntary childlessness, but evidence suggests that the incidence of secondary infertility—‘infertility in a patient who has previously conceived’ ([Anderson, 2003](#), p. 923)—is actually somewhat higher than the incidence of primary infertility ([Chandra and Stephen, 2010](#)). Older studies utilizing standardized measures of anxiety and stress have not found differences between levels of distress among women with primary as opposed to secondary infertility ([Downey and McKinney, 1992](#); [Edelmann et al., 1994](#)), but newer studies have found that women with primary infertility exhibit higher levels of distress than women with secondary infertility ([Epstein and Rosenberg, 2005](#); [Upkong, 2006](#); [Verhaak et al., 2007](#)). Older studies show that distress specific to infertility is higher among women with primary rather than secondary infertility ([Freeman et al., 1983](#); [Callan and Hennessey, 1988](#)). In order to account for the many characteristics that may be associated with general and FSD among women with infertility, we control for a number of characteristics in addition to the focal associations between type of infertility (primary or secondary) and intentionality with regard to getting pregnant.

Statement of the problem

We focus on two intersecting characteristics of infertility episodes to better understand the variance in distress levels among women meeting the medical criteria for infertility, controlling for potentially confounding characteristics. The National Survey of Fertility Barriers (NSFB) provides a way to assess several correlates of FSD and general distress among a random sample of US women of reproductive age. We therefore use these data to evaluate the following hypotheses about distress among women meeting the medical criteria for infertility:

- i. Intentionality should be associated with FSD. The infertile with intent

should have higher levels of FSD than the infertile without intent even after other variables—including wanting a child—are controlled. This relationship should persist when the sample is restricted only to women who have received treatment.

- ii. Type of infertility should be associated with FSD. Women who have not had a pregnancy (i.e. the primary infertile) should exhibit higher FSD scores than women who have been pregnant (i.e. the secondary infertile) even after other variables are controlled. This relationship should persist when the sample is restricted only to women who have received treatment.
- iii. General distress should be less sensitive to variations in the experience of infertility. General distress should be unrelated to either intentionality or type of infertility.
- iv. Age should be associated with FSD. Older women should be more distressed than younger women.
- v. Such fertility-related variables as family support and pressure, importance of motherhood, and wanting more children should be associated with FSD.
- vi. General distress should be less sensitive to fertility-related variables and more related to demographic variables that are associated with general distress in general samples.

Materials and Methods

Setting

This study was conducted in the USA, an economically and racially diverse country where costs for infertility are particularly high, where there is no universal health care, and where most states do not mandate that the costs of

infertility treatment be covered by insurance ([Chambers et al., 2009](#); [Connolly et al., 2010](#)).

Subjects

The NSFB conducted telephone interviews with 4796 women aged 25–45 years in the USA. Some of their partners were also included but are not part of this analysis. This Random Digit Dialing (RDD) sample consists of a nationally representative sample, plus an over-sample of Census central office codes with a high-minority population to ensure sufficient numbers of women for subgroup analyses. Our sample design included a prenotification letter with a \$1 or \$2 cash incentive for all telephone numbers with address matches. The incentive was changed from \$2 to \$1 following an experimental comparison built into a random sample segment that found little difference in response rate between the two amounts. Interviewing was conducted by the Survey Research Center at the Pennsylvania State University and the Bureau of Sociological Research at the University of Nebraska-Lincoln. The same interviewer training material and interviewer guides were used at both sites. Methodological information, including the methodology report, introductory letters, interview schedules, interviewer guides, data imputation procedures and a detailed description of the planned missing design can be accessed at:

<http://sodapop.pop.psu.edu/codebooks/nsfb/wave1/>. The public-access data files can be accessed at: <http://sodapop.pop.psu.edu/data-collections/nsfb>.

Screening questions were used to create additional oversamples of women who had had an infertility episode, who had never given birth, who had miscarried in the past, and/or who would like to have a baby in the future, and the study only selected 10% of women who reported having completed child bearing (the comparison group). We weight the data to account for the

disproportionate probability that women in minority groups and/or women with past or potential fertility barriers were included in the sample. Interviews were designed to take ~35 min and included detailed reproductive histories, demographic measures and attitudinal measures. A ‘planned missing’ design was used to provide a way to incorporate more indicators of key concepts while minimizing respondent burden and keeping the interview relatively short. The estimated response rate for the sample is 53.0% for the screener, which is typical for RDD telephone surveys conducted in recent years ([McCarty et al., 2006](#)). Extensive comparisons with Census data indicate our weighted sample is representative of women aged 25–45 years in the USA.

The sample for the present analysis consists of 1027 women who reported an episode of infertility in the 10 years prior to the interview. An ‘episode’ of infertility is, for the purposes of this analysis, any period of 12 months or greater during which a women had regular intercourse and was either trying to conceive or ‘okay either way’ about conception but did not conceive. Women were considered to have had an episode of infertility if they answered yes to either of the following questions: (i) ‘Was there ever a time when you were trying to get pregnant but did not conceive within 12 months?’ or (ii) ‘Was there ever a time when you regularly had sex without using birth control for a year or more without getting pregnant?’ Only women who were not breastfeeding were included. Of the women who reported an episode of infertility, 59.4% had a subsequent live birth. In analyses not shown here, we determined that eliminating women who had a live birth after infertility did not change the pattern of results, so we include them in the analysis presented here.

Measures

Fertility-specific distress

One dependent variable in this study is FSD. A number of fertility-specific measures have been developed (See especially [Keye et al., 1984](#); [Abbey et al., 1991](#); [Hjelmstedt et al., 1999](#); [Newton et al., 1999](#); [Schmidt, 2006](#); [Jacob et al., 2007](#)), but none of these measures has achieved the status of a standard measure. The measures of [Newton et al. \(1999\)](#) and [Schmidt \(2006\)](#) have been used in several studies (see e.g. [Benyamini et al., 2005](#); [Panagopoulou et al., 2006](#); [Lykeridou et al., 2009](#); [Mahajan et al., 2009](#); [Wilkins et al., 2010](#)) although they are too long for many situations. A new measure, the Fertility Quality of Life Questionnaire (FertiQoL), has recently been developed by [Boivin et al. \(2010\)](#) and tested for validity and reliability ([Verhaak et al., 2010](#)). This measure may well become a generally accepted measure of fertility distress, but it has not yet been used in many studies and was not available when we conducted our research. In addition, 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). Finally, it was necessary 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 [e.g. 46-item scale proposed by [Newton et al. \(1999\)](#)], the NSFB team created a 6-item scale comprised of questions that draw on the [Hjelmstedt et al.'s \(1999\)](#) Infertility Reaction Scale, qualitative research on infertile couples (e.g. [Greil, 1991](#)) and the clinical experience of members of the research team.

Respondents who reported having tried unsuccessfully to become pregnant for a period of at least 12 months were read the statement: ‘You tried for quite a while to get pregnant. Please tell me whether you had these reactions

when you didn't get pregnant'. Women who had a period of at least 12 months of regular intercourse but who did not say that they were trying to become pregnant were read the statement: 'You had several months of sex without using birth control without getting pregnant. Please tell me whether you had these reactions when you didn't get pregnant'. Both groups of women were then presented with a series of items and asked whether they felt this way frequently, occasionally, seldom or never. The items were: 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; I felt like a failure as a woman. The scale was computed using the mean of available items, such that it ranges from 0 to 1. Because of the planned missing design, each respondent received two thirds of the items chosen at random. Almost all (96.7%) responded to all items with which they were presented. Two of the items, 'I felt I was being punished' and 'I felt angry at God', have religious overtones; to ascertain whether religiosity may have influenced FSD scores we conducted independent samples t-tests on these items and found that neither item was significantly associated with religiosity. In addition, the correlation between the FSD scale and religiosity is 0.025 and is not significant. Higher scores indicate greater distress. This scale has an α of 0.830 for the sample used in this analysis.

General distress (CESD-10)

The other dependent variable used in this study is general distress. General distress is measured by the CESD-10 ([Andresen et al., 1994](#)), a shorter version of the well known 20-item Center for Epidemiological Studies Distress Scale (CES-D) ([Radloff, 1977](#)). The CES-D is not a diagnostic instrument but was specifically developed for use in community surveys. It is easy to administer, has been translated into Spanish, has excellent measurement properties ($\alpha = 0.860$ for this sample), and is appropriate for a

study in which explanation, and not treatment, is the central focus ([Hann et al., 1999](#)). The CES-D does not distinguish well between depressive and anxious conditions and may over-identify ‘cases’ ([Orme et al., 1986](#); [Rabkin and Klein, 1987](#); [Zich, et al., 1990](#)). The CESD-10 has been shown to have adequate reliability and validity and to be equivalent to the longer version in predictive accuracy ([Cheung et al., 2007](#); [Lee and Chokkanathan, 2008](#); [Bradley et al., 2010](#)).

Infertility type

The two focal independent variables are infertility type and intentionality with regard to pregnancy. Infertile respondents were classified as belonging to one of two groups based on whether or not they had experienced prior pregnancies. The primary infertility group includes 399 (38.9%) respondents who experienced a period of infertility before they had experienced any pregnancies. The secondary infertility group consists of 628 (61.1%) respondents who were pregnant at least once prior to an infertility episode. The medical definition of primary infertility is infertility with no prior pregnancies, but some researchers (e.g. [Epstein and Rosenberg, 2005](#); [Chandra and Stephen, 2010](#)) define ‘primary infertility’ as infertility in a woman who has not had previous children, even though she may have had a prior pregnancy. In a preliminary analysis, we divided women with infertility into three categories: women with no prior pregnancies; women with at least one prior pregnancy but no live births; and women who experienced an infertility episode but have had live births prior to experiencing an infertility episode. This preliminary analysis revealed that the 45 women with pregnancies but no live births were significantly different on FSD from women with no prior pregnancies but did not differ significantly from women with live births. In order to keep the analysis as simple and clear as possible, we combined the ‘prior pregnancy but no live

birth group’ with the ‘live birth’ group. Thus, our working definitions of primary and secondary infertility match the medical definitions of these terms. We regard women who have had no prior pregnancies as having primary infertility and women with at least one prior pregnancy as having secondary infertility.

Intentionality

Of the women who reported having an episode of unprotected regular intercourse of over 12 months, 57.7% described themselves as trying to become pregnant at the time of their infertility episode and were classified as infertile with intent. The remaining 42.3% did not report trying to become pregnant but said they were ‘okay either way’ during their infertility episode and were classified as infertile without intent.

Resource and demographic variables

We controlled for variables which previous research suggested should be related to distress. These variables are summarized in Table I.

Table I Control variables used in the analysis	
Name	Description
Demographic/resource variables	
Race/ethnicity	Standard US Census wording. Dummy variables constructed for Black, Hispanic and Asian compared with White women.
Family income	Total family income expressed in \$10 000
Economic hardship	Summative scale using three questions. Example: 'During the last 12 months, how often happen that you had trouble paying the bills' (α = 0.82)
Employment	1 = any employment, 0 = no employment
Education	Years of formal schooling
Health insurance status	'Are you covered by private health insurance, by public health insurance such as Medicaid, or some other kind of health care plan or by no health insurance?' 1 = private health insurance, 0 = all other answers

[See full table](#)

Table I. Control variables used in the analysis.

Method of analysis

We conducted two ordinary least squares (OLS) regression analyses for FSD. OLS regression is the appropriate technique where the dependent variable is quantitative and continuous. In the first analysis we regressed FSD on all variables for the entire sample of women with infertility. In the

second analysis, we limited the sample to women who received tests or treatment for infertility in order to test whether similar results would be obtained when the sample was limited to treatment seekers only. Who to include as having received tests or treatment for infertility was determined by looking at a series of questions about tests and treatment as well as by examining detailed pregnancy histories. Anyone who reported receiving specific tests or treatment for infertility was included in the ‘tests and treatment-only’ sample as well as in the full sample. Women are included in the treatment sample if they have received any tests or treatment for infertility. Only a small minority of the women in the treatment sample (17.6%) have received assisted reproduction treatments. We repeated the same two analyses using CES-D as the dependent variable. In analyses not shown here, we added an interaction term for infertility type by intentionality with regard to pregnancy. Because the interaction was not significant in any of the analyses, we do not report interaction effects in this article.

Results

Descriptive statistics

Table II presents descriptive statistics for the independent variables across the various infertility groups, showing differences among women with every possible combination of infertility type and intentionality. Table II provides several insights regarding intentionality and infertility type among women who meet the criteria for infertility. The most common image of women with infertility is that of a woman who sees herself as having explicitly tried to get pregnant and has never had a child. Yet, this group makes up only 34.5% of all of the women who meet the medical criteria for infertility.

Women with secondary infertility make up 61.1% of women with infertility and are about equally divided between the infertile without intent (i.e. not explicitly trying to become pregnant at the time of the infertility episode) (31.5%) and the infertile with intent (29.6%). The remaining group (infertile without intent, primary infertility) makes up only a small percentage of the women who meet the criteria for infertility (4.4%).

	Infertile without intent		Infertile with intent			
	1 Primary	2 Secondary	3 Primary	4 Secondary	Mean	SD
n	45	324	354	304		
% of all infertile	4.4	31.5	34.5	29.6		
Continuous variables						
FSD	0.18	0.15	0.43	0.37		
CESD	1.74	1.74	1.73	1.78		
Education	12.08	12.07	12.05	12.05		

[See full table](#)

Table II. FSD by intentionality and prior pregnancy status for entire sample (n = 1027).

FSD varies by infertility group, but CESD-10 does not. FSD is highest among the women who have the situation most commonly thought of as ‘infertile’: women with no pregnancies who were explicitly trying to conceive at the time of the infertility episode (Mean FSD = 0.43). This is significantly higher than the mean for the infertile with intent women who have had a pregnancy (Mean FSD = 0.37). Both of these means are significantly higher than the means for the infertile without intent (M = 0.18 for infertile without intent, no prior pregnancy; M = 0.15 for infertile without intent, secondary infertility).

These patterns suggest that both infertility type and intentionality are associated with FSD. Yet it is also possible that characteristics of the women in each of these groups could differ, and those differences, not infertility type/intentionality could explain the differences in FSD. We therefore examined the characteristics associated with infertility

type/intentionality. Only a few characteristics are consistent across groups: religiosity, internal medical locus of control, ethical concerns about infertility treatment, percentage Hispanic, percentage Asian percent in states with mandated insurance coverage, percentage with their first infertility episode 0–5 years ago and percentage with their first infertility episode 6–10 years ago. As is evident in Table [II](#), there are many differences in characteristics by infertility type/intentionality group, but no simple overall pattern emerged. Instead, the groups that differed from each other depended upon the specific characteristics examined.

Fertility-specific distress

We now turn to the results of the multiple regression analyses. The first set of coefficients in Table [III](#) displays the results of the OLS multiple regression of the relationship between intentionality, infertility type, control variables and FSD for the entire sample of women who have had an episode of infertility within the past 10 years. For the entire sample, women who were explicitly trying to become pregnant during the infertility episode have higher FSD scores ($\beta = 0.31$) than the infertile without intent, even when other variables—including current desire for another child—are controlled. The same relationship is also found when the sample is limited to women who have received tests or treatment ($\beta = 0.19$). For both the entire sample ($\beta = 0.08$) and for women who have received tests or treatment only ($\beta = 0.14$), women with primary infertility have higher FSD scores than women with secondary infertility.

Table III
Multiple regression analysis of effects of intentionality and prior pregnancy status on FSD.

	FSD						
	Full sample			Treatment only			
	β	SE	P	β	SE	P	
Intentionality/pregnancy status							
Intentionality	0.18	0.02	0.31	**	0.25	0.08	0.19
Primary infertility	0.05	0.02	0.08	*	0.09	0.04	0.14
Black	0.01	0.02	0.01		0.09	0.05	0.11
Hispanic	-0.03	0.02	-0.04		0.04	0.06	0.05
Asian	-0.05	0.05	-0.03		-0.04	0.08	-0.03
Income	0.00	0.00	0.03		0.00	0.00	-0.05
Employment	0.01	0.02	0.01		0.01	0.04	0.01

[See full table](#)

Table III. Multiple regression analysis of effects of intentionality and prior pregnancy status on FSD.

Of the resource and demographic variables, only age is related to FSD. As anticipated, for both the entire sample and the sample of those who have received tests or treatment, age is positively associated with FSD ($\beta = 0.07$ and $\beta = 0.12$, respectively), indicating that older women have higher FSD scores than younger women. Higher levels of social support are associated with lower FSD in both the full sample and those who received tests or treatment ($\beta = -0.15$ and $\beta = -0.08$, respectively). Of the social support and social pressure variables, only family encouragement to seek treatment is associated with FSD. For the entire sample only, women with families ($\beta = 0.08$) who encourage medical help seeking for infertility have higher average FSD scores than women who do not have encouragement. Higher importance of motherhood is associated with higher FSD for both the full sample and those who received tests or treatment ($\beta = 0.15$ and $\beta = 0.21$, respectively), as is a desire to have more children ($\beta = 0.11$ and $\beta = 0.17$, respectively) but these associations do not explain away the differences in FSD scores among women with different types of infertility and levels of intentionality. All the independent variables taken collectively account for over a quarter of the variance in FSD ($R^2 = 0.277$), and among the treatment only sample, almost half of the variance was accounted for by these variables ($R^2 = 0.465$).

General distress

Table IV presents the same analyses as Table III but now the dependent variable is CESD-10. For neither the full sample nor the sample of those who have received tests or treatment is there a significant association between either intentionality or type of infertility and CESD-10. Several of the control variables are significantly associated with CESD-10. Women who are employed have lower levels of distress in both the full sample and those who received tests or treatment ($\beta = -0.07$ and $\beta = -0.12$, respectively). Higher levels of education are associated with lower levels of CESD-10 for both the full sample and for women who have received tests or treatment ($\beta = -0.16$ and $\beta = -0.20$, respectively). For both the full sample and for women who have received tests or treatment, women with private health insurance have lower CESD-10 scores ($\beta = -0.12$ and $\beta = -0.16$, respectively) than women without private health insurance. Among the full sample only, CESD-10 is lower among women who report higher levels of social support ($\beta = -0.11$) and among women who report higher levels of religiosity ($\beta = -0.08$). All the independent variables taken collectively account for just over one-third of the variance in CESD-10 ($R^2 = 0.366$) in the full sample and almost half of the variance among women who have received tests and treatment ($R^2 = 0.429$).

Table IV
Multiple regression analysis of effects of intentionality and prior pregnancy status on CESD.

	CESD			
	Full Sample		Treatment Only	
	β	SE	β	P
Intentionality/pregnancy status				
Intentionality	0.06	0.04	0.05	0.03
Primary infertility	0.03	0.04	0.03	0.09
Black	0.05	0.05	0.04	0.23
Hispanic	-0.04	0.05	-0.03	0.00
Asian	-0.12	0.10	-0.04	-0.11
Income	0.00	0.00	-0.01	0.00
Employment	-0.08	0.04	-0.07	*

[See full table](#)

Table IV. Multiple regression analysis of effects of intentionality and prior pregnancy status on CESD.

To summarize, infertility type and intentionality with regard to pregnancy are both associated with FSD, but neither is associated with CESD-10. Other infertility-related variables, such as encouragement by family and friends to get treatment and currently wanting more children, are also associated with FSD but not with CESD-10.

Discussion

This study is one of very few studies of infertility and psychological distress that focuses on women with infertility who are not in treatment as well as those who are. Looking at those who are not in treatment allows us to (i) judge the generalizability of findings from clinic samples, (ii) begin to sort out the psychological effects of infertility from the psychological effects of infertility treatment and (iii) assess the unmet need for counseling services. In this article, we took advantage of a US population-based sample and compared results from a general sample to a sample restricted to those in treatment.

We hypothesized (Hypothesis i) that intentionality about pregnancy would be associated with FSD. Specifically, we hypothesized that women who described themselves as trying to become pregnant at the time of their infertility episode would have higher levels of FSD than women who did not describe themselves as explicitly trying to become pregnant at the time of the infertility episode. This hypothesis was supported. Our findings confirm other research we have done on intentionality with regard to becoming pregnant ([Greil and McQuillan, 2004](#); [Greil et al., 2010](#)). It is important to note that of the infertile without intent say they want more children even though they do not describe themselves as trying to become pregnant at the time of the infertility episode. Thus, it is important not to confuse

intentionality with regard to desire to become pregnant at a particular time with wanting to have another child in general. Furthermore, even when we limit the sample to only those who have received tests or treatment, the effect of intentionality remains. These results suggest that determining intentionality at the time of an infertility episode should be useful for counseling women with infertility. Further, health care providers must also be aware that even though their patients may report that they are not currently trying to get pregnant, they may, in fact, meet criteria for infertility and want to have children. Some women simply do not identify with the idea of ‘trying’ to conceive ([Greil and McQuillan, 2010](#)). As most of these women desire (more) children, informing women about treatment options could be beneficial for future treatment success.

We also hypothesized (Hypothesis ii) that women with primary infertility would have higher levels of FSD than women with secondary infertility. This hypothesis was also supported, confirming the findings of the few other—now dated—studies that have looked at the relationship between FSD and type of infertility ([Freeman et al., 1983](#); [Callan and Hennessey, 1988](#)). Infertility caregivers need to be aware that the emotional needs of women with primary infertility may differ from those of women with secondary infertility.

It is also clear that FSD proved to be much more sensitive to variations in distress among women with infertility than CESD-10 (Hypothesis iii). We did not find significant relationships between either infertility type or intentionality with CESD-10, a measure of general distress. In fact, we found very few relationships with general distress other than resource and demographic variables. At first glance, the lack of findings with regard to a measure of general distress may appear to contradict numerous reports that

infertility is associated with general distress ([Greil, 1997](#); [Fekkes et al., 2003](#); [Monga et al., 2004](#)), but it must be remembered that most of these studies were not focused on variations among women with infertility but comparisons to women without infertility. Our results suggest that general measures of distress are useful for comparing women with infertility to other populations, but fertility-specific measures are more appropriate for assessing variability in experiences among women who go through infertility (Jacob et al., 2007; [Schmidt, 2009](#)). FSD measures should therefore be useful in clinical practice as a means of identifying women who are particularly distressed by infertility. The recently developed FertiQoL ([Boivin et al., 2010](#)) should be useful for this purpose. For those in need of a shorter measure, the FSD scale employed here shows promise as a short reliable measure for assessing variation in FSD. Future research should explore the measurement properties of the FSD Scale as a diagnostic tool.

As we hypothesized (Hypothesis iv), older women have higher FSD levels than younger women. This finding is consistent with the experience of many caregivers of women and couples with infertility. As women sense that their ‘biological clocks’ are running down, they are likely to experience fertility as even more urgent and unattainable, and therefore more distressing. Yet our finding conflicts with that of [Abbey et al. \(1992\)](#) who found no association between age and FSD in a sample of treatment seekers. This discrepancy could result from slightly different measures of FSD or from the difference in samples (clinic versus population).

We hypothesized (Hypothesis v) that fertility-related variables, such as family support and pressure, importance of motherhood and wanting more children, should be associated with FSD. As previous research ([Gibson and Myers, 2002](#); [Jacob et al., 2007](#); [Slade et al., 2007](#)) has suggested, higher

perceived social support is associated with lower distress. Most of the ‘social pressure’ variables did not have significant associations with FSD. Encouragement by friends and family to seek treatment was not associated with FSD in the treatment only sample but was associated with higher FSD in the full sample. We have not seen other reports that encouragement by friends or family and partners is associated with higher FSD. This finding suggests either that not all ‘support’ from those in one's social network is positive support or that those who have higher FSD are more likely to elicit encouragement to seek medical treatment. It is also likely that ‘encouragement’ can seem like ‘pressure’ to those who do not seek medical help. Understanding how social relationships can minimize or enhance distress among women with infertility is an important area for additional research. Additionally, women with infertility could benefit from counselors working to help with strategies for managing relationships. As we expected, women who attribute greater importance to motherhood and women who desire more children exhibit higher levels of FSD than women who place less importance on having children. This dovetails with the finding of [Abbey et al. \(1992\)](#) that greater importance of children is associated with greater distress.

Because general distress is not specific to the fertility experience, we hypothesized (Hypothesis vi) that general distress would be less sensitive to fertility-related variables and more sensitive to the standard demographic variables that are associated with distress in general population studies. This hypothesis is partially supported in this study. Employment, education and having private health insurance are associated with lower general distress, although income is not. In general, our analyses support the consistent finding that general distress levels are lower with higher socioeconomic status ([Phelan et al., 2004](#)). Although [McQuillan et al. \(2003\)](#) did not find

that education or employment modified the association between infertility and general distress, their sample was much smaller than ours and they were focused primarily on comparing women with infertility to women without infertility rather than variations among women with infertility. Of the variables other than demographic and resource variables, only social support and religiosity were associated with CESD-10. Social support and religiosity were associated with well-being in other studies ([Coyne, 1991](#); [Ellison, 1991](#); [Thoits, 1995](#); [Pargament, et al., 2005](#); [Shreve-Neiger and Edelstein, 2004](#)). That all of the other variables were associated with CESD-10 in anticipated ways suggests that the null findings for the infertility-specific variables should be valid.

Researchers often emphasize statistically significant findings, but unexpected non-significant findings are also worth noting. Most infertility researchers know that women who identify as members of racial/ethnic minority groups are overrepresented among women with infertility and underrepresented among women pursuing infertility treatment compared with white women ([Bitler and Schmidt, 2006](#); [Chandra and Stephen, 2010](#)). That indicators of race/ethnicity are not associated with FSD suggests that the reason for lower treatment rate is not because these groups are less distressed by infertility. Therefore, we interpret this pattern as suggesting a serious unmet need for infertility services among women who are members of racial/ethnic minority groups.

We find no association between religiosity and FSD, similar to the finding by [Domar et al. \(2005\)](#) who found that spiritual well-being was not associated with FSD among women undergoing IVF. [Mahajan et al. \(2009\)](#) found that intrinsic religiosity was associated with adjustment to infertility, but our findings are not comparable because our religiosity measure did not

distinguish between intrinsic and extrinsic religiosity. Our finding that medical locus of control appears to conflict with the finding by [Koropatnick et al. \(1993\)](#) that internal locus of control is associated with higher infertility distress, but those authors used a measure of general locus of control and did not specifically measure medical locus of control.

It is striking that many of the variables that differentiated the more distressed from the less distressed have to do with the meaning of infertility. It seems plausible that infertility should be more distressing for women who have never achieved a pregnancy because the specter of involuntary childlessness should loom especially large for them. It also seems plausible that infertility should be more distressing to women who see themselves as having tried to become pregnant. Greater intentionality should lead to greater distress when plans are not realized. Alternatively, women who are distressed by not having a child could come to consider themselves as ‘trying’ rather than ambivalent about becoming pregnant.

Women who are infertile with intent and have had no prior pregnancies stand out as a particularly distressed group. Note also that women who place a higher value on motherhood have higher levels of FSD. This suggests that how one understands or frames infertility has important implications for levels of distress. Our findings suggest that therapy oriented toward empowering clients to reassess the meaning of infertility in their lives is a productive approach to coping with infertility. These results also suggest that perceived social pressure from family and friends can be perceived as distressing rather than supportive. We agree with [LeClair-Underberg \(2008\)](#) that empowering clients to tell friends and family what they need from them should be more helpful than being angry, or isolating themselves from friends and family who seem insensitive.

We wish that we could establish causal order for several of the associations identified in this study. For example, it is possible that perceived pressure from family and friends leads to higher distress, but it is also possible that women who are more distressed seek more encouragement from others. Although it seems plausible that women who place a higher value on motherhood will be more distressed when they are unable to achieve motherhood, it is also possible that higher levels of distress contribute to placing more value on motherhood. Because we must rely here on cross-sectional data, the causal ordering of these associations is difficult to assess. The problem is compounded because we asked women to recall events in the past. For example, we cannot know if self-reported intentionality actually preceded behavior or whether it is a retrospective construction of past events. It is plausible that women with greater intentionality with regard to becoming pregnant are likely to experience higher levels of FSD; it is also possible, however, that those who experience more distress from infertility are more likely, in retrospect, to characterize their episode as a time of explicit ‘trying’.

An additional shortcoming is that some concepts, such as FSD and CESD-10, were measured at the time of the interview whereas other variables refer to the time of the infertility episode. The associations are thus likely to be weaker than if they had been measured during the infertility episode. Although our analysis showed the same basic findings for recent infertility episodes as for episodes occurring 6–10 years ago, it is likely that for some women these responses would have been different at the time of the episode than at the time of the interview.

Despite these shortcomings, however, this study contributes to our understanding of the psychosocial impact of infertility by providing

compelling evidence that FSD differs for women with infertility depending on their type of infertility and intentionality with regard to becoming pregnant. The use of a probability-based sample that includes women who have not received tests or treatment represents a major advance over most previous studies and lends our findings greater generalizability.

Conclusion

Utilizing a large population-based sample has allowed us to test a broader range of psychosocial responses to infertility episodes than are usually found in fertility clinics, and it has enabled us to uncover the importance of intentionality and infertility type as important predictors of FSD. Infertility type and intentionality with regard to pregnancy are both related to FSD, even after controlling for other characteristics of women that should also be associated with FSD. Therefore, we argue that it is important to know the characteristics of infertility episodes in order to understand why women vary in their experiences of infertility. A better comprehension of variation in the experience of infertility should help caregivers to better understand the needs of women with infertility, including those who are not currently seeking or receiving services. Understanding variation in psychological distress therefore calls for fertility-specific measures. We hope our work will encourage more studies of women from non-clinic samples, greater use of fertility-specific measures and a continued exploration of variation in the psychological concomitants of infertility. We stress the benefits to women with infertility if counselors and physicians recognize variation among women with infertility and the need to understand what the experience means to women.

Authors' roles

A.L.G. assisted in designing the research instrument, conducted the multiple regression analysis and wrote the first draft of the manuscript. K.M.S. played a major role in preparing the data for analysis as well as in revising the manuscript. L.S. played a major role in revising the manuscript. J.M. played an instrumental role in designing the research instrument, supervised data collection, helped to conceptualize the analyses and played a major role in revising the manuscript. All authors have approved the final version of the manuscript.

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[\[Back\]](#)

Table I.

Control variables used in the analysis.

Name	Description
Demographic/resource variables	
Race/ethnicity	Standard US Census wording. Dummy variables constructed for Black, Hispanic and Asian compared with White women
Family income	Total family income expressed in \$10 000
Economic hardship	Summative scale using three questions Example: 'During the last 12 months, how often happen that you had trouble paying the bills ($\alpha = 0.82$)
Employment	1 = any employment, 0 = no employment
Education	Years of formal schooling
Health insurance status	'Are you covered by private health insurance, by public health insurance such as Medicaid, or some other kind of health care plan or by no health insurance?' 1 = private health insurance, 0 = all other answers
State coverage	0.1 = lives in a state with some form of mandated coverage for infertility treatment, 0 = lives in a state

coverage without any form of mandated coverage for infertility

Episode timing 1 = 6–10 years before the time of the interview, 0 = 0–5 years before the time of the interview

Life course variables

Age Measured in years

Never married 1 = never been married, 0 = all other marital statuses

Support/pressure variables

Social support 4-item scale based on [Sherbourne \(1991\)](#). ‘How often is each of the following kinds of support available to you if you need it?’ Example, ‘Someone to give you good advice about a crisis?’ 4 = often to 1 = never. ($\alpha = 0.84$)

Important to partner ‘It is important to my partner that we have children,’ 1 = strongly agree, 0 = all other answers

Important to parents ‘It is important to my parents that I have children’, 1 = strongly agree, 0 = all other answers

Family/friends have kids ‘Thinking about your family and friends, would you say that all, most, some, few or none of them have kids?’ 1 = strongly agree, 0 = all other answers

Friends pursue ‘Have family/friends pursued medical help to help get pregnant?’ 1 = yes, 0 = no

Partner encourage 'Did your husband/partner strongly encourage, encourage, discourage, or strongly discourage seeking medical help or was it mixed?' 1 = strongly encouraged, 0 = all other answers

Family/friends encourage 'Did your family or friends strongly encourage, encourage, discourage, or strongly discourage seeking medical help or was it mixed?' 1 = strongly encouraged, 0 = all other answers

Attitudinal variables

Importance of motherhood Constructed by averaging responses to five questions (e.g. 'Having children is important to my feeling complete as a woman') ($\alpha = 0.72.$)

Wants more children 'Would you, yourself, like to have a(nother) baby?' 1 = yes, 0 = no

Religiosity Constructed by averaging responses to four questions (e.g. 'How often do you attend religious services?') ($\alpha = 0.73$)

Internal Medical locus of control 6-item scale based on [Wallston et al. \(1978\)](#) ($\alpha = 0.71$)

Ethical concerns Constructed by averaging of responses to six scenarios concerning reproductive technology. Responses included 1 = no ethical problem, 2 = some ethical problems, 3 = serious ethical problems ($\alpha = 0.70$)

serious ethical problems ($\alpha = 0.70$)

[\[Back\]](#)

[\[Back\]](#)

Table II.

FSD by intentionality and prior pregnancy status for entire sample ($n = 1027$).

	Infertile without intent		Infertile with intent					
	1	2	3	4				
	Primary	Secondary	Primary	Secondary				
n	45	324	354	304				
% of all infertile	4.4	31.5	34.5	29.6				
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Continuous variables								
FSD	0.18	0.22	0.15	0.16	0.43	0.30	0.37	0.37
CESD	1.74	0.64	1.74	0.51	1.73	0.53	1.78	0.53
Education (years)	14.98	2.57	14.10	2.51	15.30	2.93	14.14	2.57
Age (25–45 years)	32.36	5.47	32.99	5.68	33.96	5.24	34.13	5.47
Family								

Income (× \$10 000)	5.41	3.92	5.04	3.62	6.93	4.08	5.98	3.
Social support	3.58	0.72	3.56	0.75	3.63	0.68	3.49	0.
Importance of motherhood	3.08	0.59	3.38	0.51	3.49	0.53	3.49	0.
Religiosity	−0.13	0.82	0.00	0.80	−0.08	0.85	−0.02	0.
Internal medical locus of control	2.88	0.49	2.98	0.49	2.96	0.48	2.95	0.
Ethical concerns about infertility treatment	1.62	0.62	1.54	0.56	1.51	0.53	1.59	0.
Categorical Variables	%		%		%		%	
White, non-Hispanic	51.1		45.4		60.2		49.7	
Black	22.2		32.1		19.2		24.7	

Hispanic	17.8	21.0	17.2	22.7
Asian	8.9	1.5	3.4	3.0
Employed (full or part time)	75.6	62.3	70.6	62.5
Private health insurance	73.3	63.0	76.6	65.8
State coverage	44.4	46.6	46.6	51.6
Episode 0–5 years	62.2	45.7	48.9	59.5
Episode 6– 10 years	37.8	54.3	51.1	40.5
Never married	40.0	23.1	9.9	10.5
Very important to partner	20.0	27.5	43.8	38.8
Very important to grandparents	17.8	26.2	33.6	25.3

Most friends family have kids	62.2	83.3	79.9	86.8
Friends pursue	42.2	42.9	60.5	51.3
Partner encourages	22.2	4.0	44.4	28.6
Family encourages	28.9	2.8	41.5	28.3
Wants more children	79.5	51.4	70.7	51.7
Received tests or treatment	20.0	2.5	58.8	34.2

Note: χ^2 performed for categorical variables, Analysis of Variance with Tukey post hoc for continuous variables. The post hoc column indicates which groups (1, 2, 3, & 4) are significantly different from one another. For example, '3 v 4' indicates that the 'primary/intent' group differs significantly from the 'secondary/intent' group.

CESD, Center for Epidemiology Studies-Depression.

*P < 0.05.

**P < 0.01.

***P < 0.001.

[\[Back\]](#)

[\[Back\]](#)

Table III.

Multiple regression analysis of effects of intentionality and prior pregnancy status on FSD.

	FSD							
	Full sample				Treatment only			
	B	SE	β	P	B	SE	β	P
Intentionality/pregnancy status								
Intentionality	0.18	0.02	0.31	***	0.25	0.08	0.19	*
Primary infertility	0.05	0.02	0.08	*	0.09	0.04	0.14	*
Black	0.01	0.02	0.01		0.09	0.05	0.11	
Hispanic	-0.03	0.02	-0.04		0.04	0.06	0.05	
Asian	-0.05	0.05	-0.03		-0.04	0.08	-0.03	
Income	0.00	0.00	0.03		0.00	0.00	-0.05	
Employment	0.01	0.02	0.01		0.01	0.04	0.01	
Education	0.00	0.00	-0.05		0.00	0.01	-0.04	
Private								

insurance

State coverage	-0.02	0.02	-0.04		-0.02	0.04	-0.04	
Episode 6-10 years ago	-0.01	0.02	-0.02		0.07	0.04	0.11	
Age	0.00	0.00	0.07	*	0.01	0.00	0.12	*
Never married	-0.02	0.03	-0.03		-0.11	0.09	-0.08	
Social support	-0.06	0.01	-0.15	***	-0.04	0.03	-0.08	*
Important to partner	0.00	0.02	-0.01		-0.05	0.04	-0.09	
Important to parents	0.00	0.02	0.01		0.05	0.04	0.07	
Most friends family have kids	0.03	0.02	0.05		0.09	0.05	0.11	
Friends pursue	0.00	0.02	0.00		0.03	0.04	0.05	
Partner encourages	0.04	0.02	0.06		-0.07	0.04	-0.11	

Family encourages	0.05	0.02	0.08	*	-0.01	0.04	-0.01	
Motherhood	0.08	0.02	0.15	***	0.13	0.04	0.21	***
Wants more children	0.06	0.02	0.11	***	0.11	0.04	0.17	**
Religiosity	0.00	0.01	0.01		0.01	0.02	0.02	
Internal medical locus of control	-0.01	0.02	-0.02		0.04	0.04	0.06	
Ethical concerns about infertility treatment	-0.02	0.02	-0.04		-0.02	0.04	-0.03	
Intercept	0.10	0.04		***	0.09	0.12		***
n	892				292			
R ²	0.277				0.465			

Note: The 292 'treatment-only' cases are included in the analysis of the full sample as well.

*P < 0.05.

**P < 0.01.

***P < 0.001.

[\[Back\]](#)

[\[Back\]](#)

Table IV.

Multiple regression analysis of effects of intentionality and prior pregnancy status on CESD.

	CESD							
	Full Sample				Treatment Only			
	B	SE	β	P	B	SE	β	P
Intentionality/pregnancy status								
Intentionality	0.06	0.04	0.05		0.03	0.14	0.01	
Primary infertility	0.03	0.04	0.03		0.09	0.07	0.08	
Black	0.05	0.05	0.04		0.23	0.10	0.16	
Hispanic	-0.04	0.05	-0.03		0.00	0.11	0.00	
Asian	-0.12	0.10	-0.04		-0.11	0.15	-0.04	
Income	0.00	0.00	-0.01		0.00	0.00	0.06	
Employment	-0.08	0.04	-0.07	*	-0.15	0.07	-0.12	*
Education	-0.03	0.01	-0.16	***	-0.04	0.01	-0.20	**
Private insurance	-0.13	0.04	-0.12	**	-0.25	0.10	-0.16	*

State coverage	-0.04	0.03	-0.03		-0.02	0.07	-0.01
Episode 6-10 years ago	-0.04	0.03	-0.04		0.02	0.07	0.02
Age	0.01	0.00	0.05		0.00	0.01	0.01
Never married	0.08	0.05	0.06		-0.09	0.16	-0.04
Social support	-0.08	0.02	-0.11	**	-0.03	0.05	-0.04
Important to partner	-0.05	0.04	-0.05		-0.08	0.08	-0.07
Important to parents	0.04	0.04	0.03		0.06	0.08	0.05
Most friends family have kids	-0.02	0.04	-0.01		0.09	0.08	0.06
Friends pursue	-0.02	0.04	-0.02		-0.01	0.07	-0.01
Partner encourages	-0.05	0.04	-0.04		-0.10	0.07	-0.09
Family	-0.03	0.04	-0.02		-0.10	0.07	-0.09

encourages	-0.03	0.04	-0.02		-0.10	0.07	-0.09
Motherhood	0.04	0.04	0.04		0.11	0.07	0.10
Wants more children	0.06	0.03	0.05		0.07	0.07	0.06
Religiosity	-0.05	0.02	-0.08	*	-0.05	0.04	-0.08
Internal medical locus of control	-0.02	0.03	-0.02		-0.10	0.06	-0.09
Ethical concerns about infertility treatment	0.02	0.03	0.02		0.00	0.07	0.00
Intercept	1.92	0.07		***	1.95	0.21	
n	939				298		
R ²	0.366				0.429		

Note: The 298 'treatment-only' cases are included in the analysis of the full sample as well.

*P < 0.05.

**P < 0.01.

***P < 0.001.

[\[Back\]](#)

Table of Contents

Variation in distress among women with infertility: evidence from a population-based sample†	1
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