Title: Variation in Distress among Infertile Women: Evidence from a Population-Based Sample

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Abstract

BACKGROUND: We examine variations in fertility specific distress (FSD) and general distress by variations in infertility experiences among 1.027 U.S. women who report having experienced infertility within the ten years prior to being interviewed by telephone. We compare infertile women who have had a prior pregnancy (secondary infertility) to infertile women with no prior pregnancies (primary infertility). We further distinguish between infertile women 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 (the infertile without intent). METHODS: Multiple regression analysis was conducted on self-report data from a probability-based sample of U.S. women. RESULTS: Our findings show that type of infertility (primary vs. secondary) and pregnancy intent are both 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, as measured by a short form of the Center for Epidemiological Studies Depression Scale (CESD-10), does not vary by infertility type or pregnancy intent. CONCLUSIONS: These results suggest that there is tremendous variation in women's experiences of infertility and that FSD is much more sensitive to the effects of different experiences than general distress. Primary infertile woman who were trying to become pregnant at the time of the infertility episode stand out as a particularly distressed group.

Keywords: Fertility Specific Distress, Infertility, Intentionality, Primary, Secondary

Variation in Distress among Infertile Women: Evidence from a Population-Based Sample

Introduction

Although there are many studies of psychological distress among infertile women (Greil *et al*., 2010; Henning and Strauss, 2002), 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 pregnancy intent at the time of the infertility episode. We examine variations in fertility specific distress (FSD) and general distress (CESD) by type of infertility in a nation-wide probability sample of 4,787 U.S. women, of which 1,027 have reported at least one episode of infertility within the past ten years. We compare infertile women who have had a prior pregnancy (secondary infertility) to infertile women 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 trying to become pregnant (the infertile without intent). Because characteristics of women 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 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 greater of unprotected intercourse without conception (Zegers-Hochschild *et al.,* 2009). Using this definition, the National Survey of Family Growth

(NSFG) estimates that 7.4 percent of married U.S. 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 differently 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 infertile women 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 (Fekkes *et al*., 2003; Greil, 1997 ; Monga *et al*., 2004).

Drawing conclusions from research on infertility and distress is made more difficult by several methodological limitations in prior studies. First, the infertile women 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 treatment seekers. In the United States, 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 infertile women 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 (Abbey *et al.,* 1992; Ulbrich *et al*., 1990). Fertility specific measures, however, do not permit comparison with control groups or population norms. Thus, these measures are most useful for comparisons among the infertile.

A third reason for concerns about findings in studies of the psychological consequences of infertility among women is the heterogeneity among infertile women. 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 variations in distress among infertile women has focused on differences in coping strategies and other psychological attributes (Benyamini *et al*., 2005; Miles *et al*., 2009; Peterson *et al.,* 2008, 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. Fertility specific 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. Recent research has pointed to the importance of self-definition as infertile as a key

feature in the helpseeking process (Bunting and Boivin, 2007; Greil and McQuillan, 2004; White *et al*., 2006). Because women who are more distressed by infertility should be more likely to seek help, this pattern suggests that self-definition as infertile should be associated with fertility specific distress.

Greil and McQuillan (2004) have divided infertile women 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 consciously 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 specific *intentionality* to have a child at a particular moment in time. Many women in the U.S. 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 to pregnancy and wanting a(nother) child are two conceptually separate variables, and the nature of their relationship to one another is an empirical question. Although the infertile without intent are less likely to pursue treatment (Greil *et al.*, 2009), some of them do seek treatment. While the infertile with intent do not differ from the infertile without intent with regard to general distress, they do score significantly higher on FSD.

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 (Callan and Hennessey, 1988; Freeman *et al*., 1983). In order to account for the many characteristics that may be associated with general and fertility specific distress among women with infertility, we control for a number of characteristics in addition to the focal associations between type of infertility 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 U.S. women of reproductive age. We therefore use these data to evaluate the following hypotheses about distress among women meeting the medical criteria for infertility:

1.) 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.

2.) 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.

3.) 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.

4.) Age should be associated with FSD. Older women should be more distressed than younger women.

5.) Such fertility related variables as family support and pressure, importance of motherhood, and wanting more children should be associated with FSD.

6.) General distress should be less sensitive to fertility-related variables and more related to demographic variables which are known to be related to general distress.

Materials and Methods

Setting

This study was conducted in the U.S., an economically and racially diverse country where costs for infertility are particularly high, where there is not 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 National Survey of Fertility Barriers (NSFB) conducted telephone interviews with 4,787 women aged 25 to 45 in the United States. Some of their partners were also included but are not part of this analysis. This Random Digit Dialing 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 pre-notification 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 (SRC) at the Pennsylvania State University and the Bureau of Sociological Research (BOSR) 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 or had a low likelihood of a fertility problem (the comparison group). We weight the data to account for the disproportionate probability that minority and/or women with past or potential fertility barriers were included in the sample. Interviews were designed to take approximately 35 minutes 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 age 25-45 in the United States.

The sample for the present analysis consists of 1.027 women who reported an episode of infertility in the ten 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" but did not conceive. Women were considered to have had an episode of infertility if they answered yes to either of the following questions: (1) "Was there ever a time when you were *trying* to get pregnant but did not conceive within 12 months?" or (2) "Was there ever a time when you regularly had sex without using birth control for a year or more without getting pregnant? or if they reported having a pregnancy *after* a period of at least 12 months during which they were either *trying* to become pregnant or said they were "okay either way" and during which they were not breastfeeding.

Measures

Fertility Specific Distress (FSD). One dependent variable in this study is FSD. A number of fertility-specific measures have been developed (See especially Abbey *et al*., 1991; Hjelmstedt *et al*., 1999; Jacob *et al*., 2007; Keye *et al*., 1984; Newton *et al*., 1999; Schmidt*.,* 2006), but none of these measures has achieved the status of a standard measure. Newton *et al*.'s (1999) and Schmidt's (2006) measures have been used in several studies (see e.g. Benyamini *et al.,* 2005; Lykeridou *et al.,* 2009; Mahajan *et al.,* 2009; Panagopoulou *et al.,* 2006; Wilkins *et al*., 2010) although they are too long for many situations. A new measure, the 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), for the NSFB a 6-item scale comprised of questions that draw on Hjelmsted *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 was created.

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. Of 613 respondents, 593 (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 .025 and is not significant. Higher scores indicate greater distress. This scale has an alpha of .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 = .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 (Bradley *et al*., 2010; Cheung *et al*., 2007; Lee and Chokkanathan, 2008).

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 fertility with no prior pregnancies, but some researchers (e.g. Chandra and Stephen, 2010; Epstein and Rosenberg, 2005) define "primary infertility" as

infertility in a woman who has not had previous children. In a preliminary analysis, we divided infertile women 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. 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. Women who have had no prior pregnancies are regarded as having primary infertility, while secondary infertility refers to infertility in a woman who has had at least one prior pregnancy, irrespective of the outcome.

Intentionality. Of the 613 women who reported having an episode of twelve months of unprotected regular intercourse of over twelve months, 354 (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 259 (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. *Race/ethnicity* was measured using the standard Census wording. For participants with multiple responses, "Hispanic" has first priority and "Black" has second priority. Dummy variables were constructed for Black, Hispanic, and Asian compared to White women. Those indicating only "other" races were eliminated from the analysis due to small cell counts.

Because many people are sensitive to questions about income, *family income* was measured in several stages. First, respondents were asked if their total family was less than or greater than $40,000 in the year that they were interviewed. Respondents whose family income was below $40,000 were asked a second question asking them to select ordinal categories numbered from 1 (under $5,000) to 7 ($30,000-$39,999). Respondents whose family income was above $40,000 were asked to select among ordinal categories numbered from 8 ($40,000-49,999) to 12 ($100,000 or more). We then substituted the midpoint of each income category range for the category value in order to convert this into a continuous scale. We selected $140,000 as a reasonable estimate of the midpoint for category 12. In addition to income, we also measured perceived *economic hardship* using the following questions: 1) "During the last 12 months, how often did it happen that you had trouble paying the bills," 2) "During the last 12 months, how often did it happen that you did not have enough money to buy food, clothes, or other things your household needed," and 3) "During the last 12 months, how often did it happen that you did not have enough money to pay for medical care?" This is a unidimensional scale with high reliability ($\alpha = .82$). *Employment* was measured by a single binary variable indicating either full-time or part-time employment compared to no employment. *Education* was measured in years. *Health insurance status* was assessed by the question, "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?" It was coded so that 1 indicates that the respondent has private health insurance while all other options are coded as 0. Only 15 states mandate insurance coverage for infertility, and they vary in the type and extent of coverage offered. In the absence of a simple way to classify types of mandates, we simply employed a binary variable with 1 indicating that the respondent lives in a state with some form of *mandated coverage* for infertility treatment and 0

indicates that a respondent lives in a state without any form of mandated coverage for infertility. Because of the economic context of infertility treatment in the U.S., variables related to economic and insurance issues are particularly relevant to the US context.

We created a dummy variable to measure how long ago in the past the episode occurred. A value of 1 indicates that the first infertility episode occurred 6-10 years before the time of the interview. The reference category is 0-5 years before the time of the interview. Recency of episode is treated as a demographic/resource variable based on the assumption that women whose infertility episodes were more recent may have had more treatment options available to them. It is also important to include a dummy variable for recency of episode for methodological reasons. We are asking women to recall events that occurred in the past; thus, women with more recent infertility episodes may recall these events more clearly. In addition, although the infertility episode occurred in the past, we are measuring distress in the present. Women with more recent episodes might be more distressed because of the lesser amount of time that has passed since the episode. Therefore, a finding that recency of episode is **not** associated with FSD would give us confidence these methodological factors are less likely to be confounding our results.

Life Course Variables. *Age* was measured in years. *Never married* is a dummy variable distinguishing women who have never been married from women in all other marital statuses.

Social Support and Social Pressure. Perceived *social support*, a scale based on work by Sherbourne and Stewart (1991), was measured by how often the following four kinds of support were available if needed: "someone to give you advice about a crisis," "someone to give you information to help you understand a situation," "someone whose advice you really want," and "someone to share your most private worries and fears with." Responses include: (1) = often, (2)

= occasionally, (3) = seldom, and (4) = never. The scale was created by averaging item responses (α = .84). *Social pressure* to have children was included in the model because it might be expected to affect distress levels. Social pressure was assessed via the following questions: "It is important to my partner that we have children," "It is important to my parents that I have children", and "Thinking about your family and friends, would you say that all, most, some, few or none of them have kids?" A response of "Strongly agree" was coded as 1 and all other responses were coded as 0. Several other social pressure questions were included as well. *Friends pursue* was assessed by a yes/no question: "Have family/friends pursued medical help to help get pregnant?" *Partner encourage* and *family/friends encourage* were derived from answers to questions about whether respondents were encouraged to seek medical help. Possible responses were: "strongly encouraged," "encouraged," "discouraged, "Strongly discouraged," and "Mixed." Answers of strongly encouraged" or encouraged' were coded as 1; all other answers were coded as 0.

Attitudinal Variables. Importance of motherhood was constructed by averaging responses to five questions (e.g. "Having children is important to my feeling complete as a woman") and is a single factor scale with an alpha of .72. *Wants More* was coded 1 for those responding 'yes' to the question: "Would you, yourself, like to have a (nother) baby?" *Religiosity* was measured by four questions (e.g. "How often do you attend religious services?"). Because these four items were measured on different scales, they were combined by first standardizing and then taking the mean. These items form a single factor and have an alpha of .73. *Internal Medical Locus of Control* was a unidimensional 6-item scale based on the work of Wallston, Wallston, and DeVellis (1978). The scale was designed to assess the degree to which health outcomes are seen as under one's control. It has an alpha of .71 *Attitudes about ethics of assisted reproductive*

technology (ART) were measured by responses to six scenarios to which respondents replied (1) no ethical problem, (2) some ethical problems, or (3) serious ethical problems ($\alpha = .70$).

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. In the first analysis we regressed FSD on all variables for the entire sample of infertile women. 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 obtain 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 ART. We repeated the same two analyses using CESD 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 I presents descriptive statistics for the independent variables across the various infertility groups, showing differences among women with every possible combination of infertility type and intention status. Table I provides several insights regarding intention status

and pregnancy status among women meeting infertility criteria. The most common image of infertile women is that of a woman who sees herself as trying to get pregnant and has never had a child. But 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 infertile women and are about equally divided between women who were not consciously trying to become pregnant at the time of the infertility episode (31.5%) and those who were (29.6%). The remaining group (no intent, primary infertility) makes up only a small percentage of the women who meet the criteria for infertility (4.4%).

[Table I about here]

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 consciously trying to conceive at the time of the infertility episode (M = .43). This is significantly higher than the mean for women with intent who have had a pregnancy (M = .37). Both of these means are significantly higher than the means for the women without intent (M = .18 for no intent, no prior pregnancy; M =.15 for no intent, secondary infertility).

These patterns suggest that both infertility type and intention toward pregnancy 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, percent Hispanic, percent Asian percent in states with mandated insurance coverage, percent with their first infertility episode 0-5 years ago, and percent with their first infertility episode 6-10 years ago.

There are many differences in characteristics between the women in the different infertility type/intentionality groups, but no simple overall pattern emerged. Instead, the groups that differed from each other depended upon the specific characteristics examined. Education level is highest among the primary with intent group and lowest among the secondary with intent and secondary without intent groups. Women in the secondary with intent category were significantly older than women in the secondary without intent category. Women with intent and no prior pregnancies had the highest family income, and there is also a significant difference in income between the secondary with intent group and the secondary without intent group. Social support is higher among the primary with intent group than among the secondary with intent group. Women with no pregnancies and no intent are lower than all of the other groups on importance of motherhood. Women with no intent score lower on importance of motherhood than women with intent, regardless of whether or not there has been a prior pregnancy. White women are over-represented among those with primary infertility, and Black women are most likely to be in the secondary infertility categories. Asian women are more likely to be in the primary without intent group. Most of the women who met the criteria for infertility are employed, but the percent employed is highest among women with primary infertility with intent and lowest among the both secondary groups. More than half of the women have private health insurance across all of the statuses, but women with primary infertility are more likely to have private health insurance. The differences between statuses in the percentage with their first episode in the last five years are significant at the .001 level. The highest percentage of women is in the primary infertility/no intent status and the lowest in the secondary infertility/ no intent status. The proportion with their first episode 6-10 years ago also differs by status. The highest percentage is in the primary infertility/intent status and the lowest is in the primary infertility/no

intent group. Women in the primary/no intent group were much more likely never to have been married than women in the other groups.

The percentage saying that having a child is very important to their partner is generally higher among those with intent. Perceived pressure from grandparents is highest for women with primary infertility and intent and lowest in the primary/no intent group. Most of the women have family and friends with children, but women with secondary infertility are more likely to have family or friends with children. Having friends and family with children is more likely among women with primary than among women with secondary infertility, and the primary/intent group is the most likely of all to report having friends or family with children. Women in the primary/intent category are most likely, and women in the secondary/no intent category least likely, to say they have partners who encourage them to seek medical help for infertility and to say they have family members who encourage them to seek medical help. Women with secondary infertility are less likely than women with primary infertility to want more children, but the pattern is similar for each intention status. Women in the primary/intent group are the most likely, and women in the secondary/no intent group the least likely, to have received tests or treatment.

Fertility-Specific Distress

We now turn to the results of the multiple regression analyses. The first set of coefficients in Table II 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 ten years. For the entire sample, women who were trying to become pregnant during the infertility episode have higher FSD scores (Beta= .18) than infertile women without intent, even when other variables – including 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=.19). For both the entire sample (Beta=.05) and for women who have received tests or treatment only (Beta=.09), women with primary infertility have higher FSD scores than women with secondary infertility.

[Table II about here]

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 has a positive association with FSD (Beta=.07 and Beta=.12, respectively), showing that older women have higher FSD scores than younger women. Higher levels of social support are associated with lower FSD in both samples (Beta= -.15 and Beta=.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 partners family (Beta=.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 entire sample and for those who have received tests or treatment (Beta=.15 and Beta=.21 respectively), as is a desire to have more children (Beta=.11 and Beta=.17 respectively), but these associations do not explain away the differences in FSD scores among women of 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=.277), and among the treatment only sample, almost half of the variance was accounted for by these variables (R^2=.465).

General Distress

Table III presents the same analyses as Table II, 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 relationship between either intentionality or type of infertility and CESD-10. Several of the control variables are significantly related to CESD-10. Being employed is associated with lower levels of distress for both samples (Beta=-.07 and Beta=-.12 respectively). Higher levels of education (Beta=-.09) are associated with lower levels of CESD-10 for both the full sample and for women who have received tests or treatment (Beta= -.10 and Beta=-.20 respectively). For both samples, women with private health insurance have lower CESD-10 scores (Beta=-.12 and Beta=-.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=.-.11) and among women who report higher levels of religiosity (Beta=-.08). All the independent variables taken collectively account for just over one-third of the variance in CESD-10 (R^2=.366) in the full sample and almost half of the variance among women who have received tests and treatment (R^2=.429)

(Table III about here)

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 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 infertile women who are not in treatment as well as those who are. Looking at those who are not in treatment allows us to judge the generalizability of findings from clinic samples. Examining those not in treatment also allows us to begin to sort out the psychological effects of infertility from the psychological effects of infertility treatment. Finally, looking at those not in

treatment allows us to assess the unmet need for counseling services. In this article, we have looked at variations in FSD and general distress among a U.S. population-based sample of infertile women.

We hypothesized (Hypothesis 1) 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 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 most infertile women without intent nonetheless want more children. Thus, it is important not to confuse specific intentionality about becoming pregnant at a particular time with general desire for a child. Furthermore, even when we limit the sample to only those who have received tests or treatment, the effect of intentionality remains. Intentionally with regard to becoming pregnant at the time of the infertility episode may thus be an important factor to consider in counseling infertile women. Further, health care providers must also be aware that even though their patients may report that they are not trying to get pregnant, they may, in fact, meet criteria for infertility. Some women simply do not identify with the idea of "trying" to conceive. As most of these women desire (more) children, informing women about treatment options may be beneficial for future treatment success.

We also hypothesized (Hypothesis 2) 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 (Callan and Hennessey, 1988; Freeman *et al*., 1983).

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 infertile women than CESD-10 (Hypothesis 3). 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. (The exception to this generalization, having to do with resource and demographic variables, will be discussed below.) 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 (Fekkes *et al*., 2003; Greil, 1997; Monga *et al*., 2004), but it must be remembered that most of these studies were not focused on variations *among* infertile women. Our results suggest that general measures of distress are useful for comparing infertile women 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). Fertility-specific distress measures may 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 Fertility Specific Distress scale employed here shows promise as a short reliable measure for assessing FSD. Future research should explore the measurement properties of the Fertility Specific Distress Scale.

As we hypothesized (Hypothesis 4), older women have higher FSD levels than younger women. This finding is consistent with common sense and with the experience of many caregivers of infertile women and couples. 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 be from slightly different measures of FSD or from the difference in samples (clinic versus population).

We hypothesized (Hypothesis 5) that such fertility-related variables 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 to seek treatment by friends and family 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 despite others suggesting that they do so. Understanding how social relationships can minimize or enhance distress among women with infertility is an important area for additional future 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 6) that general distress would be less sensitive to fertility-related variables and more sensitive to 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 were related to the effects of infertility on general distress, their sample was much smaller than ours and they were focused primarily on comparing infertile women to non-infertile women rather than to looking for variations within the infertile population. Of the variables other than demographic and resource variables, only social support and religiosity were associated with CESD-10 – similar to studies of well-being (Coyne, 1991; Ellison, 1991; Pargament, *et al.,* 2005; Shreve-Neiger and Edelstein*.,* 2005; Thoits, 1995). 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.

Although researchers have a natural tendency to emphasize significant findings, sometimes non-significant findings are also worth noting. It is well known 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 to majority 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. There is a serious unmet need for infertility services among these groups.

Our finding that religiosity is not related to FSD is consistent with the observation by Domar *et al.* (2005) that spiritual well-being is not associated with FSD among IVF women. Mahajan *et al.* (2009) found that intrinsic religiosity was related to 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 they 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 with regard to FSD have to do with the *meaning of infertility.* It seems plausible that infertility should be more distressing to women who have never achieved a pregnancy because the specter of involuntary childlessness may 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 may 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 just "hoping" to become pregnant.

Women who have had no prior pregnancies and who are infertile with intent 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 their infertility is a productive approach to coping with infertility. These results also suggest that perceived social pressure from family and friends may be associated with higher distress. This indicates that empowering clients to educate members of their social support networks about how they can be most helpful could yield more

positive experiences than being angry or isolating form friends and family (LeClair-Underberg, 2008).

A major limitation of this study is that we cannot 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 get 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 it, it is also possible that higher levels of distress may result in women 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 whether "intent" and "no intent" actually preceded behavior or whether they are retrospective constructions 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 "trying."

An additional shortcoming is that some concepts, such as FSD and CESD-10, were measured at the time of the interview while other variables refer to the time of the infertility episode. Therefore the associations are likely to be weaker than if they had been measured during the episode of infertility. Although our analysis showed the same basic findings for recent infertility episodes as for episodes that occurred 6-10 years ago, it is likely that for some women these responses would have been different at the time of the episode than they were 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 fertility specific distress differs for infertile women 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. It is important to know the characteristics of infertility episodes 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 infertile women, 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 non-clinic samples, greater use of fertility specific measures, and continued exploration of variation the psychological concomitants of infertility. We argue the benefits to infertile women if counselors and physicians recognize variation among infertile women and the need to understand what the experience means to women.

Author's Roles

Arthur L. Greil assisted in designing the research instrument, conducted the multiple regression analysis, and wrote the first draft of the manuscript. Karina M. Shreffler and played a major role in preparing the data for analysis as well as in revising the manuscript. Lone Schmidt played a major role in revising the manuscript. Julia McQuillan 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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References

Abbey A, Andrews FM and Halman LJ. Gender's role in responses to infertility. *J Clin Psychol* 1991;**15**:295-316.

Abbey A, Andrews FM and Halman LJ. Psychosocial, treatment, and demographic predictors of the stress associated with infertility. *Fertil Steril* 1992;**57**:122-128.

Anderson DM. Dorland's Illustrated Medical Dictionary, 27th edn, 2003. Saunders/Elsevier, New York.

Andresen EM, Malmgren JA, Carter WB and Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiological Studies Depression Scale). *Am J Prev Med* 1994;**10**:77-84.

Benyamini Y, Gozlan M, and Kokia E. Variability in the difficulties experienced by women undergoing infertility treatments. *Fertil Steril* 2005;**83**:275-283.

Bitler M and Schmidt L. 2006. Health disparities and infertility: impacts of state-level insurance mandates. *Fertil Steril* 2006;**85**:858-865.

Boivin J, Takefman J and Braverman A. http://www.fertiqol.org. Last accessed December, 2010.

Bradley KL, Bagnell AL and Brannen CL. Factorial validity of the center for epidemiological studies depression 10 in adolescents. *Issues Ment Health* 2010;**31**:408-412.

Bunting L and Boivin J. Decision-making about seeking medical advice in an internet sample of women trying to get pregnant. *Hum Reprod* 2007;**22**:1662-1668.

Callan VJ and Hennessey JF. The psychological adjustment of women experiencing infertility. *Br J Med Psychol* 1988;**61**:137-140.

Chambers GM, Sullivan EA, Isihara O, Chapman MG and Adamson GD. The economic impact of assisted reproductive technology: a review of selected developed countries *Fertil Steril* 2009;**91**:2281-2294.

Chandra A and Stephen EH. Declining estimates of infertility in the United States: 1982–2002. *Fertil Steril* 2006;**86**:516-523

Chandra A and Stephen EH. Infertility service use among U.S. women: 1995 and 2002. *Fertil Steril* 2010;**93**:725-736.

Cheung YB, Liu KY and Yip PSF. Performance of the CES-D and its short forms in screening suicidality and hopelessness in the community. *Suicide Life Threat Behav* 2007;**37**:79-88.

Connolly MP, Hoorens S and Chambers GM. The costs and consequences of assisted reproductive technology: an economic perspective. *Hum Reprod* 2010;**16**:603-613.

Coyne JC. Social factors and psychopathology: stress, social support, and coping processes. *Annu Rev Psychol* 1991;**42**:401-425.

Domar AD, Penzias A, Dusek JA, Magna A, Merari D, Nielsen B and Paul D. The stress and distress of infertility: does religion help women cope? *Sexuality, Reproduction, and Menopause* 2005;**3**:45-51.

Downey J and McKinney M. The psychiatric status of women presenting for infertility evaluation. *Am J Orthopsychiatry* 1992;**62**:196-205.

Edelmann RJ, Connolly KJ and Bartlett H. Coping strategies and psychological adjustment of couples presenting for IVF. *J Psychosom Res* 1994;**38**:355-364.

Ellison C. Religious involvement and subjective well-being, *J Health Soc Behav* 1991; **32**:80-99.

Epstein YM and Rosenberg HS. Depression in primary versus secondary infertility egg recipients. *Fertil Steril* 2005;**83**:1882-1884.

Fekkes M., Buitendijk SE, Verrips GHW., Braat DDM, Brewaeys AMA., Dolfing JG, Kortman M, Leerentveld RA and Macklon NS. Health-related quality of life in relation to gender and age in couples planning IVF treatment. *Hum Reprod* 2003;**18**:1536-1543.

Freeman EW, Garcia CW and Rickels K. Behavioral and emotional factors: comparisons of anovulatory infertile women with fertile and other infertile women. *Fertil Steril* 1983;**40**:195-201.

Gibson DM and Myers JE. The effects of social coping resources and growth-fostering relationships on infertility stress in women. *J Mental Health Couns* 2002;**24**:68-80.

Greil AL. Not Yet Pregnant: Infertile Couples in Contemporary America. 1991. Rutgers University Press, New Brunswick, NJ.

Greil AL. Infertility and psychological distress: a critical review of the literature. *Soc Sci Med* 1997;**45**:1679-1704.

Greil AL and McQuillan J. Help-seeking patterns among infertile women. *J Reprod Infant Psychol* 2004;**22**:305-319.

Greil AL, McQuillan J, Johnson KM, Slauson-Blevins KS and Shreffler KM. 2009. The hidden infertile: infertile women without pregnancy intent in the United States." *Fertil and Steril* 2009;**93**:2080-2083.

Greil AL, Slauson-Blevins and McQuillan J. The experience of infertility: a review of recent literature. *Sociol Health Illn* 3**2**;140-162.

Hann D, Winter K and Jacobson P. Measurement of depressive symptoms in cancer patients: evaluation of the center for epidemiological studies depression scale (ces-d). *J Psychosom Res* 1999;**46**:437-443.

Henning K and Strauss B. Psychological and Psychosomatic Aspects of Involuntary Childlessness: State of Research at the end of the 1990's. 2002. Ashland, OH: Hogrefe and Huber.

Hjelmstedt A, Andersson L, Skoog-Svanberg A, Bergh T, Boivin J and Collins A. Gender differences in psychological reactions to infertility among couples seeking IVF- and ICSI-treatment. *Acta Obstet Gynecol Scand* 1999;**78**:42-48.

Jacob MC, McQuillan J and Greil AL. Psychological distress by type of fertility barrier. *Hum Reprod* 2007;**22**:885-894.

Keye WR Jr, Deneris A and Sullivan J. The infertility reaction scale. Unpublished manuscript. 1984. University of Utah Medical Center.

Koropatnick S, Daniluk J and Pattinson HA. Infertility: a non-event transition, *Fertil Steril* 1993;**59**:163-171.

LeClair-Underberg C. Communicatively coping with miscarriage: the impact of emotional support and narrative coherence on women's individual and relational well-being. Dissertation. University of Nebraska-Lincoln. 2008.

Lee AE and Chokkanathan S. Factor structure of the 10-item CES-D scale among community dwelling older adults in Singapore. *Int J Geriatr Psychiatry* 2008;**23**:592-597.

Lykeridou K, Gourounti K, Deltsidou A, Loutradis D and Vaslamatzis G(2009) The impact of infertility diagnosis on psychological status of women undergoing fertility treatment. *J Reproductive Infant Psychol* 2009;**27**:223-237

Mahajan NN, Turnbull DA, Davies MJ, Jindal UN, Briggs NE, and Taplin JE. Adjustment to infertility: the role of intrapersonal and interpersonal resources/vulnerabilities. *Hum Reprod* 2009;**24**:906-912.

McCarty C, House M, Harman J and Richards S. Effort in phone survey response rates: the effects of vendor and client-controlled factors. *Field Methods* 2006;**18**:172-188

McQuillan J, Greil AL, White L and Jacob MC. Frustrated fertility: infertility and psychological distress among women. *J Marriage Fam* 200,:**65**:1007-1018.

McQuillan J, Greil AL and Shreffler KM. 2010. Pregnancy intentions among women who do not try: focusing on women who are ok either way. *Maternal Child Health J* 2010;DOI:10.1007/s 10995-0-10-0604.

Miles LM, Keitel M, Jackson M, Harris A and Licciardi F. Predictors of distress in women being treated for infertility. *J Reprod Infant Psychol* 2009;**27**:238-257.

Monga M, Alexandrescu B, Katz SE, Stein M and Ganiats T. Impact of infertility on quality of life, marital adjustment, and sexual function. *Urology* 2004;**63**:126.

Newton CH, Sharrard S and Glavac I. The fertility problem inventory: measuring perceived infertility-related stress. *Fertil Steril* 1999;**72**:54-62.

Orme JG, Reis J and Herz EJ. Factorial and discriminant validity of the center for epidemiological studies depression (CES-D) scale. *Clin Psychol* 1986;**42**:28-33.

Panagopoulou P, Vedhara, K, Gaintarzti and Tarlatzis B. Emotionally expressive coping reduces pregnancy rates in patients undergoing in vitro fertilization. *Fertil Steril* 2006;86;672-677.

Pargament KI, Magyar-Russell G, and Murray-Swank N. The sacred and the search for significance: religion as a unique process *J Soc Issues* 2005; **61**:665-687.

Peterson, BD, Pirritano M, Christensen U, Boivin J, Block J and Schmidt L. The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatments. *Hum Reprod* 2009;**2**:1656-1664.

Peterson BD, Pirritano M, Chistensen U and Schmidt L. The impact of partner coping in couples experiencing infertility. *Hum Reprod* 2008;**23**:1128-1137.

Phelan JC, Link BG, Diez-Roux A, Kawachi I and Levin B. "Fundamental causes" of social inequalities in mortality: a test of the theory. *J Health Soc Behav* 2004;**45**:265-285.

Rabkin JG and Klein DF. The clinical measurement of depressive disorders. In AJ Marsella, RMA Hirschfeld and MM Katz (eds), The Measurement of Depression. 1987.Guilford Press, New York, pp. 30-83.

Radloff L. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;**1**:385-401.

Schmidt L. Infertility and assisted reproduction in Denmark; epidemiology and psychological consequences, Medical Dissertation. *Dan Med Bull* 2006;**53**:390-

Schmidt L. Social and psychological consequences of infertility and assisted reproduction-what are the research priorities? *Hum Fertil* 2009;**12**:14-20.

Sexton MB, Byrd MR and von Kluge S. Measuring resilience in women experiencing infertility using the CD-RISC: examining fertility-related stress, general distress, and coping styles. *J Psychiatr Res* 2010;**44**:236-241.

Shreve-Neiger AK and Edelstein BA. Religion and anxiety; a critical review of the literature. *Clin Psychol Rev* 2004;**24**:379-397.

Slade P, O'Neill CO, Simpson AJ and Lashen H. The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. *Hum Reprod* 2007;**22**:2309-2317.

Thoits P. Stress, coping, and social support: where are we? what do we know? *J Health Soc Behav* 1995; **35**:53-79.

Ulbrich PM, Coyle AT, and Llabre MM. Involuntary childlessness and marital adjustment: his and hers. *J Sex Marital Ther* 1990;**15**:147-158.

Upkong D. Mental health of infertile women in Nigeria. *Turk Psikiyatri Derg* 2006;**17**:1-7.

Van den Broeck U, D'Hooghe T, Enzlin P and Demyttenaere K. Predictors of psychological distress in patients starting IVF treatment: infertility-specific versus general psychological characteristics. *Hum Reprod* 2010;**25**:1471-1480.

Verhaak CM, Aarts JWM, Boivin J, Kremer JAM and Van Empel IW. Measuring quality of life in infertility using the FertiQoL. *Hum Reprod* 2010;**25** (supp.):i17.

Verhaak CM, Smeenk JMJ, Evers AWM, Kremer JAM, Kraaimaat FW and Braat DDB. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum Reprod Update* 2007;**13**:27-36.

Wallston KA, Wallston BS and DeVellis R. Development of the multidimensional health locus of control (MHLC) scales. *Health Educ Monogr* 1978;**6**:160-170.

White L, McQuillan J, Greil AL and Johnson DR. Infertility: testing a helpseeking model. *Soc Sci Med* 2006;**62**:1031-1041.

Wilkins KM, Warnock, JK and, Serrano E. Depressive symptoms related to infertility and infertility treatments. *Psychiatr Clin North Am* 2010;**33**:309-321.

Wischmann T, Stammer H, Scherg H, Gerhard I and Verres R. Psychosocial characteristics of infertile couples: a study by the "Heidelberg Fertility Consultation Service," *Hum Reprod* 2001;**16**:1753-1761.

Zegers-Hochschild F, Adamson GD, de Mouzon J, Ishihara O, Mansour R, Nygren K, Sullivan E and van der Poel S. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary on ART terminology, 2009. *Hum Reprod* 2009;**24**:2683-2687.

Zich JM, Atkinson CC and Greenfield TK. Screening for depression in primary care clinics: the CES-D and the BDI. *Int J Psychiatr Med* 1990;**20**:259-277.

Table I. Fertility Specific Distress by intentionality and prior pregnancy status for entire sample (N=1027).

	No Intent				Intent				
	1 Primary		2 Secondary		3 Primary		4 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***	**Post Hoc**
Continuous Variables									
Fertility-specific distress	.18	.22	.15	.16	.43	.30	.37	.26	1,2 v 3, 4; 3 v 4
CESD	1.74	.64	1.74	.51	1.73	.53	1.78	.52	
Education (years)	14.98	2.57	14.10	2.51	15.30	2.93	14.14	2.78	2,4 v 3
Age (25-45)	32.36	5.47	32.99	5.68	33.96	5.24	34.13	5.14	2 v 4
Family Income (x $10,000)	5.41	3.92	5.04	3.62	6.93	4.08	5.98	3.38	2 v 3,4; 3 v 4
Social support	3.58	.72	3.56	.75	3.63	.68	3.49	.72	3 v 4
Importance of motherhood	3.08	.59	3.38	.51	3.49	.53	3.49	.49	1 v 2,3,4; 2 v 3
Religiosity	-.13	.82	.00	.80	-.08	.85	-.02	.80	
Internal medical locus of control	2.88	.49	2.98	.49	2.96	.48	2.95	.50	
Ethical concerns about infert treat	1.62	.62	1.54	.56	1.51	.53	1.59	.53	
Categorical Variables	%		%		%		%		P
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 impt 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: Chi-square performed for categorical variables, ANOVA with Tukey post hocs for continuous variables.
*p<.05; **p<.01; ***p<.001.

Table II. Effects of intentionality and prior pregnancy status on fertility specific distress.

	Fertility Specific Distress							
	Full Sample				Treatment Only			
	B	SE	Beta	P	B	SE	Beta	P
Intention/Pregnancy Status								
Intentionality	.18	.02	.31	***	.25	.08	.19	*
Primary infertility	.05	.02	.08	*	.09	.04	.14	*
Black	.01	.02	.01		.09	.05	.11	
Hispanic	-.03	.02	-.04		.04	.06	.05	
Asian	-.05	.05	-.03		-.04	.08	-.03	
Income	.00	.00	.03		.00	.00	-.05	
Employment	.01	.02	.01		.01	.04	.01	
Education	.00	.00	-.05		.00	.01	-.04	
Private insurance	.02	.02	.03		-.03	.05	-.04	
State coverage	-.02	.02	-.04		-.02	.04	-.04	
Episode 6 to 10 years ago	-.01	.02	-.02		.07	.04	.11	
Age	.00	.00	.07	*	.01	.00	.12	*
Never married	-.02	.03	-.03		-.11	.09	-.08	
Social Suport	-.06	.01	-.15	***	-.04	.03	-.08	*
Important to partner	.00	.02	-.01		-.05	.04	-.09	
Important to parents	.00	.02	.01		.05	.04	.07	
Most friends family have kids	.03	.02	.05		.09	.05	.11	
Friends pursue	.00	.02	.00		.03	.04	.05	
Partner encourages	.04	.02	.06		-.07	.04	-.11	
Family encourages	.05	.02	.08	*	-.01	.04	-.01	
Motherhood	.08	.02	.15	***	.13	.04	.21	***
Wants more children	.06	.02	.11	***	.11	.04	.17	**
Religiosity	.00	.01	.01		.01	.02	.02	
Internal medical locus of control	-.01	.02	-.02		.04	.04	.06	
Ethical concerns about infert treat	-.02	.02	-.04		-.02	.04	-.03	
Intercept	.10	.04		***	.09	.12		***
N	***892***				***292***			
R2	.277				.465			

* p<.05; ** p<.01; *** p<.001

Table III. Effects of intentionality and prior pregnancy status on CESD.

	CESD							
	Full Sample				Treatment Only			
	B	SE	Beta	P	B	SE	Beta	P
Intention/Pregnancy Status								
Intentionality	.06	.04	.05		.03	.14	.01	
Primary infertility	.03	.04	.03		.09	.07	.08	
Black	.05	.05	.04		.23	.10	.16	
Hispanic	-.04	.05	-.03		.00	.11	.00	
Asian	-.12	.10	-.04		-.11	.15	-.04	
Income	.00	.00	-.01		.00	.00	.06	
Employment	-.08	.04	-.07	*	-.15	.07	-.12	*
Education	-.03	.01	-.16	***	-.04	.01	-.20	**
Private insurance	-.13	.04	-.12	**	-.25	.10	-.16	*
State coverage	-.04	.03	-.03		-.02	.07	-.01	
Episode 6 to 10 years ago	-.04	.03	-.04		.02	.07	.02	
Age	.01	.00	.05		.00	.01	.01	
Never married	.08	.05	.06		-.09	.16	-.04	
Social Support	-.08	.02	-.11	**	-.03	.05	-.04	
Important to partner	-.05	.04	-.05		-.08	.08	-.07	
Important to parents	.04	.04	.03		.06	.08	.05	
Most friends family have kids	-.02	.04	-.01		.09	.08	.06	
Friends pursue	-.02	.04	-.02		-.01	.07	-.01	
Partner encourages	-.05	.04	-.04		-.10	.07	-.09	
Family encourages	-.03	.04	-.02		-.10	.07	-.09	
Motherhood	.04	.04	.04		.11	.07	.10	
Wants more children	.06	.03	.05		.07	.07	.06	
Religiosity	-.05	.02	-.08	*	-.05	.04	-.08	
Internal medical locus of control	-.02	.03	-.02		-.10	.06	-.09	
Ethical concerns about infert treat	.02	.03	.02		.00	.07	.00	
Intercept	1.92	.07		***	1.95	.21		
N	***939***				***298***			
R2	.366				.429			

* p<.05; ** p<.01; *** p<.001