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January 2007

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Psychological distress by type of fertility barrier

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BACKGROUND: We examined fertility-specific distress (FSD) and general distress by type of fertility barrier (FB). METHODS: In a random sample telephone survey, 580 US women reported their fertility intentions and histories. Six groups of women were identified: (i) no FBs, (ii) infertile with intent, (iii) infertile without intent, (iv) other fertility problems, (v) miscarriages and (vi) situational barriers. Multiple regression analyses were used to compare groups with FBs. RESULTS: Sixty-one percent reported FBs and 28% reported an inability to conceive for at least 12 months. The infertile with intent group had the highest FSD, which was largely explained by (a) self-identification as infertile and (b) seeking medical help for fertility. The no FB group had a mean Center for Epidemiological Studies Depression scale score above the commonly used cut-off of 16, although 23% of the women with FBs did score above 16. CONCLUSIONS: FBs are common. Self-identification as infertile is the largest source of FSD. More women with FBs had elevated general distress than women without FBs; mean general distress was below 16 for all FB groups. It may be that, for some women (even those with children), FBs can have lasting emotional consequences, but many women do heal from the emotional distress that may accompany fertility difficulties.

Key words: distress/infertility/survey

Introduction

Clinical lore and empirical research are rife with the notion that infertility is distressing. Clinicians report that many people dealing with infertility feel grief and depression, anger, guilt, shock or denial, anxiety and loss of control (Dunkel-Schetter and Lobel, 1991). They may feel so distressed that they may ask for help as they become worried about their own mental health. Alternatively, they may fear to ask for help, lest treatment be denied them because they are emotionally unstable (Greil, 1997).

In spite of the intensity of the emotional responses seen and reported, in studies with control groups that use standardized measures of distress, most have found that the infertile are not significantly more likely to be clinically depressed than fertile controls (Freeman *et al.*, 1983; Adler and Boxley, 1985; Paulson *et al.*, 1988). One notable and often-cited exception is a study using both the Beck Depression Inventory (BDI) (Beck *et al.*, 1961; Beck and Beamesderfer, 1974) and the Center for Epidemiological Studies Depression scale (CES-D) (Radloff, 1977) to compare 338 infertile women with 39 controls (Domar *et al.*, 1992). This study reported that significantly more women scored as depressed in the

infertile group compared with the control group. In fact, the authors did not find a significant difference between the groups on the CES-D, where they used the commonly recommended cut-off score of 16 (Boyd *et al.*, 1982). The group difference they reported was found when the authors used a BDI cut-off of 9 to identify the depressed women. Beck himself suggests a cut-off of 21 in research studies and 13 when using the BDI to diagnose depression clinically (Beck and Beamesderfer, 1974). If the recommended cut-off of 21 had been used, the percentage of women identified as depressed by the BDI would have dropped from 36.7% to less than 8.4%.

Other studies, without control groups, compare the distress scores of people with infertility to norms for community populations and for clinically ill groups. These studies generally find that people with infertility score as more distressed than persons with no reported problems, but less distressed than those with clinical mental illnesses (see Wright *et al.*, 1991; Morrow *et al.*, 1995 for examples). This finding appears to be true of the Domar *et al.* study described above, where both the BDI and the CES-D mean scores for the infertile group were significantly greater than that for the control group, even though both were below the recommended

cut-offs for identifying depression. Similarly, people with infertility have scored within the normal range on standardized tests such as the MMPI, and yet report their infertility as the most distressing thing that has ever happened to them (Freeman *et al.*, 1985). All these findings are consistent with observations made by both Greil (1991) and Wright *et al.* (1991) that distress is more representative of within-person changes than between-group differences, that is, individuals feel more or very distressed compared with what is normal for them.

The empirical literature rarely acknowledges that almost everything we know about the psychosocial consequences of infertility is drawn from cross-sectional observations of people who are currently seeking medical assistance for conception. This was true when Stanton and Dunkel-Schetter (1991) raised the issue, and it continues to be true today (with notable exceptions; see King 2003 and McQuillan *et al.*, 2003). Because most studies are of treatment seekers, it is impossible to know to what extent subjects are self-selected. Those who present themselves for treatment may be more (or less) distressed than others with FBs. In addition, it is difficult to know to what extent distress is caused by the infertility as opposed to the treatments and the feedback one gets in the course of treatment (such as IVF progress). Studying only those being treated for infertility means it is impossible to know if the results obtained are specific to medically diagnosed infertility or if they can be generalized to those with other FBs. It is also unclear whether distress varies by specific type of FB (such as infertility with or without intent to conceive, history of miscarriage, problems like sterilization regret or even situational barriers, such as not having a partner). Without comparing women with different types of FBs, it is difficult to determine whether general or fertility-specific measures of distress are better able to capture their experiences. Limiting the study population to infertility treatment seekers means that there may be limited variation on other variables that may be relevant to the relationship between infertility and distress. In particular, such studies are unable to control for whether or not subjects self-identify as infertile. Finally, we continue to know very little about the long-term natural course of the emotional distress that has been observed clinically among the infertile. We do not know whether those with a history of FBs continue to experience distress years after they first encountered an FB, nor do we know if distress is likely to lessen if those women become mothers. We know even less about the emotional responses, short and long term, of those who do not seek medical assistance.

In this paper, we examine a random, non-clinic sample of groups of women who have or are experiencing different types of FBs, to see if levels of fertility specific distress (FSD) and general distress differ by type of barrier. Because there is an established cut-off score for the CES-D, we also examine the odds of having elevated distress by type of FB. In addition, we explore a wide range of variables implicated in research on infertility specifically, and stressful life events in general. We seek answers to the following questions: Is distress (FSD and general) associated with type of FB? Is any association between FBs and specific or general distress explained by relevant individual characteristics, circumstances or infertility-related actions (e.g. motherhood, employment, relationship status, religiosity, valuing motherhood, age, resources, social support)? Do responses to FBs (i.e. self-identifying as infertile or seeking medical help) mediate any association between FBs and distress? Do motherhood or attitudes toward the value of motherhood modify any association between FBs and distress?

In an effort to begin to explore these questions, we analysed cross-sectional data on a subset of 580 women who participated in a 2002 telephone survey. The subset we primarily analysed contains 248 women who reported a history of FBs and completed the FSD questions. This paper focuses on their reports of both FSD and general distress and on variables that might explain the amounts of distress reported. Because a survey, such as this one, does not allow for random assignment of groups, we asked questions that might allow us to control for differences between the groups. We examined some variables because past research suggested that they might be related to the experience of distress, and some were included because they are thought to enhance coping and adaptation.

Materials and methods

This study was approved by the IRB at the University of Nebraska-Lincoln.

Sample

For this study, the households of women aged 25–50 from 12 states in the upper Midwest USA were selected through random-digit dialing. The details of the sampling method and of the sample have been reported elsewhere (McQuillan *et al.*, 2003; Greil and McQuillan, 2004). The overall response rate was 63%. Comparison of this sample with Census data for the 12 states shows that the sample closely mirrors the population of women by age. As designed, the sample over-represented African-Americans: 15% of the sample is African-American compared with 10% of women aged 25–50 in these states. As is common in telephone surveys, the sample over-represented college-educated women: 36% of the sample compared with 27% in the census.

Of the 580 women in the sample, almost two-thirds (61%) experienced some type of FB. For various reasons, 105 women with FBs were not asked the questions about FSD which comprise the scale that is the primary outcome variable in these analyses. The interview programming skipped 63 of the women and 5 were excluded because of programming errors. This pilot study has allowed us to catch these flaws and correct them in a larger study currently under way. In addition, 37 women refused to answer the questions. Comparison of the characteristics of the 68 women missed due to programming errors and those included in our analyses suggest that it is unlikely that the 68 women missed because of our programming have caused any systematic error. It is more difficult to evaluate the impact of the 37 women who refused the questions.

This paper focuses primarily on the 248 women who did have FBs and who answered the FSD items.

Measures

To obtain the items of any of the scales we developed, contact the corresponding author.

Fertility groups

Women were asked about their fertility goals and histories, and six groups were formed. Women in the first group, 'no FBs' were not considered in this examination of distress by type of FB except for one supplemental analysis.

'Infertile with intent' includes the 107 women who tried for more than 12 months to conceive any of their pregnancies or who had ever tried to get pregnant for more than 12 months without success.

Fifty-six women were classified as 'infertile without intent' because they reported regular unprotected intercourse for more than a year without conception but did not report that they were trying to get pregnant.

The 'other fertility problems' group includes 33 women who do not fit medical definitions of infertility but who wanted children (or more children) and reported barriers such as their own or their partner's surgical sterilization or advice from a doctor not to have more children (nine women who had a baby despite their doctor's advice are not counted here) or they just reported that difficulty in getting pregnant kept them from having babies they wanted.

The 20 women in the 'miscarriage only' group had at least one miscarriage and did not meet the criteria for infertility with or without intent or other fertility problems. Nine women had one miscarriage, nine women had two, one woman had three and one woman reported nine miscarriages.

Women were included in the 'situational barriers' to fertility group if they did not meet the criteria for biomedical infertility, if they intended to have a child in the future, if they had not yet had a child and if they were 35 years or older. Examples of situational barriers are: having a partner who does not want to have children, having a job that made it too difficult to have children, not being able to afford children and having care obligations for family members that interfere with childbearing. Most of the 32 women in this group reported more than one barrier.

Distress

Fertility specific distress. There is no established instrument to assess emotional responses to all the categories of FBs we have defined. Thus, we constructed two series of questions that draw on Hjelmstedt *et al.*'s (1999) Infertility Reaction Scale, qualitative research on infertile couples (Greil, 1991) and clinical experience. One series assesses infertility-specific distress and the other assesses distress-specific to situational FBs. These were Likert type items with a four point scale (frequently, occasionally, rarely, never). Although the items for these two series of questions generally differ because of the different experiences of biomedical versus situational FB experiences, there are four similar items. From these four items, we constructed an FSD scale that allows comparisons across type of FB. For women with infertility (with or without intent), other fertility problems or two or more miscarriages, the questions were in the past tense. For women with situational FBs, the questions were in the present tense. Despite this, the questions are almost the same and when we combine the items, the internal consistency is very good ($\alpha = 0.83$). The items are: I felt cheated by life; I felt guilty about somehow causing our fertility problems; I felt seriously depressed about it; I felt like a failure as a woman.

General distress (CES-D). The general distress dependent variable is the 20-item CES-D used to measure depressive symptoms (Radloff, 1977). Developed specifically for use in community surveys, it does not distinguish well between depressive and anxious conditions and may over-identify 'cases'(Rabkin and Klein, 1987; Zich *et al.*, 1990). The CES-D is appropriate for a study in which explanation,

and not treatment, is the central focus (Hann *et al.*, 1999). We used the CES-D to measure the general distress the women have been feeling in the last 2 weeks. Possible scores range from 0 to 60, and a cut-off score of 16 is usually used to identify 'cases' with depression or anxiety (Boyd *et al.* 1982). Actual diagnosis requires additional information such as the severity and duration of the symptoms and whether symptoms interfere with activities. A mean score of 24.4 has been reported for mixed samples of psychiatric patients (Radloff, 1977).

Possible explanatory variables

We asked participants about a range of variables that theory and/or past research suggest should predict or explain how women respond when faced with an FB, and we controlled for these variables in our multiple regression analyses.

Abortion history. There is some evidence that abortions are under-reported in survey research by perhaps 50% (Smith *et al.*, 1999; Jones and Forrest, 1992). Nonetheless, some women in each of the FB groups reported having had abortions. These reports, ranging from 5 to 18%, did not differ significantly across the groups. We added a dummy variable for having had an abortion and examined interaction terms for this variable by each FB group to discern if abortions increase distress in this population of women reporting FBs.

Social identity variables

Social identities. We included dummy variables to capture occupancy of the primary social roles available to women: mother, spouse and employee. Although isolating the 30 women who had step, adopted or foster children but not biological children had little effect on results, the centrality of biological parenthood to issues of infertility led us to code them separately. Having biological motherhood means the respondent gave birth to at least one child. We coded social motherhood for women without biological children who reported an adoption, a very close relationship to a stepchild or foster children (through a formal program or informally). The omitted group is women who have neither biological nor social children. Because previous research has shown that distress scores differ between married and cohabiting women (Brown, 2000), relationship status was coded using two dummy variables that contrast currently married and currently cohabiting women with unpartnered women. For the third primary social role of employee, a code of 1 was used for women who said that they were employed full time or part time and 0 for all other women.

Individual-level issues

Religiosity. Greil's (1991) interviews with infertile married couples revealed the importance of religiosity in how they coped with infertility. Our 3 item scale ($\alpha = 0.77$) averages responses to the following Likert items: In general, how much would you say your religious beliefs influence your daily life? About how often do you pray? How close do you feel to God most of the time? Higher scores indicate more religiosity.

Desire for more children. All respondents were asked 'Looking to the future would you, yourself, like to have baby?' Women who answered 'definitely yes' or 'probably yes' were coded as 'wants more children'.

Social-level issues

Concerns about having children are connected to wider social expectations. These expectations are tied to *age*, measured simply in years, to the expectations of one's own parents, and to the *social value of*

motherhood. Women who agreed or strongly agreed with the statement: 'It is important to my parents that I have children' were coded as 'parents desire grandchildren'. The social value of motherhood is the mean score of four Likert items ($\alpha = 0.77$): 'I can see a number of advantages to having no children'; 'Women who don't want children are unnatural'; 'I feel I would be incomplete as a woman if I could not have a child.'; and 'I can visualize a happy life without children'.

Enabling conditions

Resources. More resources are usually associated with more mastery and therefore lower distress (Mirowsky and Ross, 2001). Because the analytic sample consists only of women with FBs, the association is likely to be different. This group of women tends to be older than the general population, and the resources-to-distress association is weaker for older women (Mirowsky and Ross, 2001). Additionally, Scritchfield (1995) argues that women with more resources are used to achieving goals and therefore are more, not less, distressed by infertility than women with fewer resources. We measure three kinds of resources: *education, income* and *racial/ethnic (majority)* status. Education is measured as the number of years completed at the time of the interview. Family income was reported in 13 categories, and in our analyses, we use dollar equivalents of the midpoint of each group. Majority race/ethnic status is coded as White/non-Hispanic or other.

Expressive social support. Social support can facilitate coping with difficult life circumstances and in many studies has been found to be a buffer against distress. Social support is measured by eight items taken from a social support survey designed to tap medically relevant social support (Sherbourne and Stewart, 1991). On a four point Likert scale ($\alpha = 0.93$), respondents were asked how often various forms of social support (e.g. someone to give you good advice about a crisis, someone to share your most private worries and fears with) were available when they need it.

Predisposing conditions

Ill health is related to psychological distress. In addition, perhaps women who consider themselves generally healthy are more surprised when they encounter FBs and may have more difficulty accepting them. Therefore, we ask about both *chronic health conditions* and *general health*. We asked about chronic health conditions with a dichotomous yes/no item: 'Do you have any permanent health or physical condition that restricts your ability to move around or limits dressing, bathing, eating, working, or keeping house?' To assess general health, we asked 'In general, would you say your health is excellent, good, fair, or poor?' Higher scores indicate better general health. Because the data are cross-sectional, we do not know specifically if women considered their FBs to be health problems; however there was no indication of multicollinearity.

Responses to infertility cues among those with FBs

Self-identity as infertile. All respondents were asked the following yes/no question: Do you think of yourself as someone who has, or has had, fertility problems? All but three of the women who answered this question affirmatively were infertile with intent. We did not include those three women in the analyses. Of the 107 infertile with intent, 57% self-identify as infertile.

Sought any medical help is a variable identifying women who consulted a doctor about infertility, had medical tests or treatments for infertility problems or sought other medical help for conception. This variable was constructed to include women who gave an affirmative response to any of a series of questions asking about medical help seeking for conception, but women with situational barriers were not asked these questions.

Data analysis

To assess initial differences between FB groups we used SPSS to conduct ANOVA tests for means, followed by Tukey's honest significant difference for multiple *post hoc* tests between all of the groups. We used ordinary least squares multiple regression to assess the associations between FBs and distress (both FSD and CES-D), controlling for relevant potentially confounding variables. This procedure allows us to include dummy variables indicating membership in each of the FB groups compared to the omitted group, infertile with intent. The coefficients for the FB dummy variables provide the mean difference between each group and the omitted category. When the control variables are added to the model, the FB coefficients provide the adjusted mean differences. Multiple regression provides a way to obtain the adjusted means, to see the associations between the control variables and distress among women with FBs and to assess the combined effect of a particular FB and motherhood status or motherhood attitudes and distress through interaction variables

We assess associations in three ways. The B coefficient indicates the amount of change in the dependent variable (FSD or CES-D distress) for a one unit change in the independent variable, controlling for the other variables in the model. The values of the B coefficient are in units of the dependent variable. The β coefficient indicates the amount of change in the standardized scores of the dependent variable for a one unit change in the standardized scores of the independent variables. The B coefficient is converted into the β coefficient by multiplying it by the ratio of the standard deviation of the independent variable, divided by the standard deviation of the dependent variable. B is useful when the absolute value of the dependent variable or comparisons of associations across samples is of interest. The β coefficient is useful for comparing the strength of associations within a sample, because it standardizes the coefficients (removing the effect of the different sizes of units among the independent variables). Because β depends upon the sample standard deviations, it should not be used in cross-sample comparisons. The effect size is calculated by dividing the B coefficient by the standard deviation of the dependent variable. It is useful for assessing the practical magnitude of the effect of an independent variable, because variables can be statistically significant without having a substantial practical effect.

In a supplemental analysis employing logistic regression, we also examined the CES-D as a dichotomous variable with a cut-off of ≥ 16. (Ordinary least squares multiple regression is not appropriate when using a dichotomous dependent variable, because the dichotomous outcome introduces an element of non-linearity that violates the assumptions of multiple regression analysis.) Logistic regression transforms the dichotomized outcome into the log odds of having a high score ($=1$) and provides estimates of the change in the log odds of high distress for a one unit change in the predictor variables.

We also performed a chi-square analysis to assess the amount of CES-D distress in women with FBs compared with women with no FBs. We did this by comparing the number of women above and below the CES-D cut-off of ≥ 16 in the group of 248 women with FBs and the group of 227 women without FBs. The 105 women excluded from the primary analyses were also excluded from this supplemental analysis.

Table I. Variable means and standard deviations or percentages by fertility barrier group among a random sample of 248 Midwestern women

	Infertile with intent (n = 107)		Infertile, without intent (n = 56)		Other fertility problems (n = 33)		Miscarriage only (n = 20)		Situational barriers (n = 32)		Total (n = 248)	
	Mean (%)	SD	Mean (%)	SD	Mean (%)	SD	Mean (%)	SD	Mean (%)	SD	Mean (%)	SD
Psychological distress												
Fertility-specific distress (FSD)	1.84	0.84	1.27	0.67	1.33	0.60	1.26	0.50	1.18	0.32	1.51	0.75*,a
CES-D summary score	11.65	10.48	10.96	8.12	13.76	9.41	6.10	5.59	9.47	8.46	11.05	9.39**,b
Have CES-D scores 16+	27.10	%	21.43	%	36.36	%	5.00	%	12.50	%	23.39	%**,b
Social identities and experiences												
Biological mother	84.00	%	89.00	%	88.00	%	80.00	%	0	%	74.60	%*,c
Social mother only	6.00	%	2.00	%	9.00	%	5.00	%	28.13	%	8.00	%*,c
Voluntarily child free	0.00	%	0.00	%	3.00	%	0.00	%	0.00	%	0.00	%
Had an abortion	5.00	%	18.00	%	12.00	%	10.00	%	12.50	%	10.08	%
Married	80.00	%	61.00	%	58.00	%	80.00	%	21.88	%	65.00	%*,c
Cohabiting	5.00	%	5.00	%	12.00	%	5.00	%	9.38	%	6.00	%
Employed	77.00	%	73.00	%	73.00	%	80.00	%	84.38	%	76.61	%
Individual-level issues												
Religiosity scale	4.60	0.85	4.39	1.00	4.53	1.01	4.18	1.33	4.40	0.94	4.48	0.96
Desire a(nother) child	45.00	%	30.00	%	45.00	%	20.00	%	34.38	%	38.31	%
Social-level issues												
Social value of motherhood	2.71	0.47	2.57	0.58	2.69	0.52	2.64	0.47	1.76	0.53	2.55	0.59*,c
Parents desire grandchildren	38.00	%	45.00	%	45.00	%	55.00	%	21.88	%	39.92	%
Age over 40	50.00	%	36.00	%	61.00	%	45.00	%	28.13	%	44.76	%**,d
Age now in years	39.66	6.57	37.23	7.19	40.88	6.39	38.35	6.64	38.88	5.86	39.07	6.67
Enabling conditions												
Education in years	14.08	2.21	13.69	2.16	13.76	2.70	14.80	2.33	16.00	3.14	14.26	2.50*,e
Family income in $1000	5.64	2.59	5.06	2.14	4.88	2.83	7.31	2.64	5.93	2.84	5.58	2.62***,f
White, non-Hispanic	76.00	%	70.00	%	76.00	%	90.00	%	78.13	%	76.00	%
Social support	3.63	0.54	3.62	0.55	3.43	0.75	3.75	0.37	3.77	0.43	3.63	0.56
Predisposing conditions												
Has a chronic health condition	35.00	%	27.00	%	33.00	%	10.00	%	31.25	%	30.24	%
General health	2.99	0.81	2.93	0.78	2.79	0.65	3.30	0.47	3.03	0.86	2.98	0.77
Cognitive response to cues												
Self-identity as infertile	57.00	%	0.00	%	0.00	%	0.00	%	0.00	%	24.60	%*,a
Behavioural response to cues												
Sought any medical help	49.00	%	7.00	%	9.00	%	5.00	%	n/a	–	24.19	%*,a

Honest significant difference results, P-value at least <0.05.
[a]Infertile with intent versus all other categories.
[b]Miscarried versus other infertility.
[c]Situational versus all else.
[d]Situational versus other infertility.
[e]Situational versus infertile with, infertile without and other infertility.
[f]Miscarried versus infertile without intent and other infertility.
*$P < 0.05$ (ANOVA results).
**$P < 0.01$ (ANOVA results).
***$P < 0.001$ (ANOVA reuslts).

Results

In this study, we compared FSD and CES-D levels across FB groups. The mean FSD for the infertile with intent group is significantly higher than for each of the other four FB groups. The CES-D results are different: only the miscarriage only group and the other infertility problems group differ significantly (Table I). Although the mean CES-D scores for all FB groups are below the case cut-off score of 16, 23% of these women with FBs do have scores of 16 or higher. As one might expect after examining the mean CES-D differences, women with other fertility problems are the most likely (36%), and women who have had miscarriage only are the least likely (5%), to have clinically relevant ($\geq$16) CES-D scores. The overall percentage of those with clinically relevant CES-D scores in the FB groups is higher than the percentage of those in our larger sample who reported no FBs (16%), and this difference is statistically significant ($\chi^2 = 4.23$, df = 1, $P = 0.040$).

As expected, there are statistically significant differences between the FB groups on several of the independent variables. Self-identity as infertile occurred only among those who were infertile with intent (57%) and sought any medical help occurred mostly (49%) among those meeting the criteria for infertile with intent (Table I).

We next turn to the multivariate analyses to assess if the differences between FB groups are explained by characteristics of the women in each group. In the first model, the omitted category is the infertile with intent (Model 1, Tables II and III). In the second model, the omitted category is further refined to include those with average scores on all of the continuous variables and zeroes on the categorical variables (e.g. women who are not mothers or are voluntarily child free, have not had an abortion, are not married or cohabiting, are not employed, do not desire a(nother) child, whose parents do not desire a grandchild, are under 40 years, are in minority racial/ethnic

Table II. Fertility-specific distress by fertility barrier (FB) group and control variables among Midwestern women with FBs ($n = 248$)

	Model 1			Model 2			Model 3			Model 4		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
FB groups												
Infertile without intent	−0.57	0.12	−0.32*	−0.50	0.12	−0.28*	−0.07	0.13	−0.04	−0.06	0.13	−0.03
Other fertility problems	−0.51	0.14	−0.23*	−0.49	0.14	−0.22**	−0.06	0.15	−0.03	−0.06	0.15	−0.03
Miscarriage only	−0.58	0.17	−0.21**	−0.60	0.17	−0.22**	−0.13	0.18	−0.05	−0.10	0.17	−0.04
Situational barriers	−0.66	0.14	−0.30*	−0.70	0.20	−0.31*	−0.17	0.20	−0.07	−0.13	0.20	−0.06
Identities and experiences												
Biological mother				−0.14	0.17	−0.08	−0.05	0.16	−0.03	−0.04	0.16	−0.02
Social mother only				0.20	0.20	0.07	0.12	0.18	0.04	0.17	0.18	0.06
Voluntarily child free				−0.45	0.74	−0.04	−0.35	0.69	−0.03	−0.34	0.68	−0.03
Had an abortion				0.04	0.15	0.02	0.05	0.14	0.02	0.07	0.14	0.03
Married				−0.06	0.14	−0.04	−0.08	0.13	−0.05	−0.09	0.12	−0.06
Cohabiting				−0.18	0.21	−0.06	−0.10	0.20	−0.03	−0.14	0.19	−0.04
Employee				0.22	0.11	0.13***	0.15	0.10	0.08	0.12	0.10	0.07
Individual level												
Religiosity				0.02	0.05	0.02	0.00	0.05	0.00	0.00	0.05	0.00
Desire a(nother) child				0.26	0.11	0.17***	0.18	0.10	0.12	0.20	0.10	0.13*
Social level												
Value of motherhood				0.15	0.11	0.12	0.14	0.10	0.11	0.12	0.10	0.09
Parents desire grandchildren				0.13	0.10	0.09	0.09	0.09	0.06	0.10	0.09	0.06
Over 40 years old				−0.12	0.10	−0.08	−0.07	0.09	−0.05	−0.05	0.09	−0.03
Enabling conditions												
Education				0.00	0.02	0.00	−0.00	0.02	−0.01	−0.00	0.02	−0.01
Family income				0.06	0.02	0.20***	0.04	0.02	0.14	0.04	0.02	0.13
White, non-Hispanic				0.13	0.12	0.08	0.10	0.11	0.06	0.09	0.11	0.05
Social support				−0.13	0.08	−0.10	−0.15	0.08	−0.11	−0.16	0.08	−0.12***
Predisposing conditions												
Chronic health condition				0.00	0.10	0.00	−0.02	0.10	−0.01	−0.03	0.10	−0.02
General health				−0.12	0.06	−0.12	−0.08	0.06	−0.08	−0.07	0.06	−0.07
Cognitive response												
Self-identity as infertile							0.81	0.13	0.46*	0.57	0.15	0.33*
Behavioural response												
Sought any medical help										0.37	0.13	0.21**
Constant[a]	1.84	0.07*		1.13	0.36**		0.83	0.33***		0.85	0.33**	
Adjusted R^2			0.14*			0.19***			0.31*			0.33**

Adjusted R^2 P-value is for the change in R^2.
[a]Includes women who are infertile (with intent) in Model 1 and who have the average score on continuous variables (all are mean centred) and the 0 value on dummy variables in Models 2, 3 and 4.
*$P < 0.05$.
**$P < 0.01$.
***$P < 0.001$.

groups and do not have a chronic illness; Model 2, Tables II and III). The third model assesses the mediating effects of 'self-identifies as infertile.' The omitted category further includes those who do not self-identify as infertile (Model 3, Tables II and III). The final model adds a variable that measures whether or not women sought help for infertility, and the omitted category then includes those who did not seek help (Model 4, Tables II and III).

The first model in Table II shows that women who have experienced infertility with intent have the highest FSD, because all of the other FB groups have significantly lower average scores. These differences are not mediated by variables often thought to contribute to distress among those with FBs, such as whether one has become a mother (Model 2 in Table II). Instead, the initial differences in FSD between the infertile with intent and the other FB groups are explained by the variables self-identity as infertile and sought any medical help (see Models 3 and 4 in Table II). Overall, one-third of the variance in FSD is explained when all of the variables are added to the model (adjusted $R^2 = 0.33$).

Adding the control variables increased the adjusted R^2 by only 5% (from 0.14 to 0.19) and had little effect on the coefficients for the FB groups. Among this group of women with FBs, only three of the control variables were statistically significantly associated with FSD: being an employee, a desire for a(nother) child and family income (Model 2 in Table II). Women who were employed ($B = 0.22$, $P < 0.05$) and who desired a(nother) child ($B = 0.26$, $P < 0.05$) had higher FSD scores. Consistent with Scritchfield's (1995) expectations, increasing income was also associated with higher FSD ($B = 0.06$). Only the coefficient for desire for a(nother) child persists in the final model. In addition, controlling for self-identity as infertile and having sought any medical help for infertility increased the coefficient for social support ($B = −0.16$, $P < 0.05$). More social support is associated with less FSD.

Women who are infertile with intent who also self-identify as infertile have substantially higher FSD than women who are infertile with intent but do not self-identify as infertile (in Model 4 of Table II, $B = 0.57$, $P < 0.001$ and the standard

Table III. CES-D by fertility barrier (FB) group and control variables among Midwestern women with FBs ($n = 248$)

	Model 1			Model 2			Model 3			Model 4		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
FB group												
Infertile without intent	−0.69	1.53	−0.03	−1.84	1.38	−0.08	−2.15	1.63	−0.10	−2.16	1.64	−0.10
Other fertility problems	2.10	1.85	0.08	0.07	1.65	0.00	−0.24	1.87	−0.01	−0.24	1.88	−0.01
Miscarriage only	−5.55	2.26	−0.16*	−3.00	2.02	−0.09*	−3.33	2.24	−0.10	−3.37	2.25	−0.10
Situational barriers	−2.20	1.87	−0.08	−2.53	2.29	−0.09	−2.92	2.55	−0.10	−2.96	2.56	−0.11
Identities and experiences												
Biological mother				−1.75	2.00	−0.08	−1.81	2.01	−0.08	−1.83	2.02	−0.08
Social mother only				−0.13	2.33	−0.00	−0.07	2.34	0.00	−0.14	2.36	−0.00
Voluntarily child free				11.85	8.66	0.08	11.79	8.70	0.08	11.78	8.72	0.08
Had an abortion				3.57	1.80	0.11*	3.57	1.81	0.11*	3.54	1.82	0.11
Married				1.43	1.60	0.07	1.44	1.60	0.07	1.45	1.60	0.07
Cohabiting				0.43	2.47	0.01	0.38	2.48	0.01	0.42	2.49	0.01
Employee				0.35	1.26	0.02	0.40	1.27	0.02	0.43	1.28	0.02
Individual level												
Religiosity				−0.14	0.62	−0.01	−0.13	0.62	−0.01	−0.13	0.62	−0.01
Desire a(nother) child				1.36	1.25	0.07	1.41	1.26	0.07	1.39	1.27	0.07
Social level												
Value of motherhood				−0.19	1.24	−0.01	−0.18	1.24	−0.01	−0.16	1.24	−0.01
Parents desire grandchild				0.48	1.10	0.03	0.52	1.11	0.03	0.50	1.12	0.03
Over 40 years old				−2.95	1.16	−0.16*	−2.98	1.17	−0.16*	−3.00	1.17	−0.16*
Enabling conditions												
Education				−0.07	0.25	−0.02	−0.07	0.25	−0.02	−0.07	0.25	−0.02
Family income				−0.51	0.26	−0.14	−0.50	0.26	−0.14	−0.50	0.26	−0.14
White, non-Hispanic				−2.82	1.44	−0.13	−2.80	1.44	−0.13	−2.79	1.44	−0.13
Social support				−5.28	0.98	−0.31**	−5.27	0.98	−0.31**	−5.25	0.99	−0.31**
Predisposing conditions												
Chronic health condition				−0.03	1.22	0.00	−0.01	1.22	−0.00	0.01	1.23	0.00
General health				−2.76	0.74	−0.23**	−2.79	0.75	−0.23**	−2.80	0.75	−0.23**
Cognitive response												
Self-identity as infertile							−0.59	1.65	−0.03	−0.29	1.99	−0.01
Behavioural response												
Sought any medical help										−0.46	1.72	−0.02
Constant[a]	11.65	0.90**		15.61	4.15**		15.82	4.20**		15.79	4.21**	
Adjusted R^2			0.02*			0.07*			0.29			0.29

Adjusted R^2 P-value is for the change in R^2.
[a]Includes women who are infertile (with intent) in Model 1, and who have the average score on continuous variables (all are mean centred) and the 0 value on dummy variables in Models 2, 3 and 4.
*$P < 0.05$.
**$P < 0.001$.

deviation for FSD is 0.75; therefore, the effect size $= 0.57/0.75 = 0.80$ or over three-fourths of a standard deviation higher). The association is even stronger when the help-seeking variable is not in the model (Model 3, Table II, $B = 0.81$, $P < 0.001$). The difference in FSD between those who self-identify as infertile and those who do not ($B = 0.57$) is larger than the difference in FSD between those who sought any medical help and those who did not ($B = 0.37$).

In contrast to the FSD models, self-identity as infertile and sought any medical help did not help explain the variance in CES-D scores (Model 4 in Table III). Overall, 14% of the FSD variance is explained by FB, but only 2% of CES-D is explained by FB. Three variables in the final CES-D model (Model 4 in Table III) are associated with lower or decreasing general distress: age (over 40 years), social support and general health.

The pattern of associations is very similar when the dichotomized version of the CES-D is the outcome measure (Table IV). Initially, none of the FB groups are associated with general distress differently from the infertile with intent. After the control variables are included in the model, the negative coefficient for situational barriers becomes statistically significant, showing a substantially lower risk of high CES-D scores for women with situational barriers compared with the infertile with intent ($B = -2.06$, SE $= 0.82$, Exp(B) $= 0.13$, $P < 0.05$). The association is even stronger when the self-identify as infertile and help-seeking dummy variables are included in the model ($B = -2.12$, SE $= 0.89$, Exp(B) $= 0.12$, $P < 0.05$). Neither self-identifying as infertile nor having sought any medical help was associated with the odds of having a high CES-D score.

Additional analyses assessing interaction terms for the combined effect of parental status and FB group or the combined effect of motherhood attitudes and FB group did not add significantly to the models. Therefore, it is unlikely that the association between FB and distress differs by parental status or attitudes towards motherhood; however, it is also possible that the sample is too small to detect an effect.

Table IV. Logistic regression of dichotomized CES-D (16+ = 1, less than 16 = 0) by fertility barrier (FB) group and control variables among Midwestern women with FBs ($n = 248$)

	Model 1			Model 2			Model 3			Model 4		
	B	SE	Exp(B)	B	SE	Exp(B)	B	SE	Exp(B)	B	SE	Exp(B)
FB group												
Infertile without intent	−0.31	0.39	0.73	−0.73	0.47	0.48	−0.77	0.54	0.46	−0.77	0.54	0.46
Other fertility problems	0.43	0.42	1.54	0.12	0.51	1.13	0.08	0.58	1.08	0.08	0.58	1.08
Miscarriage only	−1.95	1.05	0.14	−1.73	1.12	0.18	−1.78	1.16	0.17	−1.79	1.16	0.17
Situational barriers	−0.99	0.58	0.37	−2.06	0.82	0.13*	−2.12	0.89	0.12*	−2.12	0.89	0.12*
Identities and experiences												
Biological mother				−0.37	0.67	0.69	−0.38	0.67	0.69	−0.38	0.67	0.69
Social mother only				0.27	0.79	1.31	0.28	0.79	1.32	0.26	0.80	1.30
Voluntarily child free[b]												
Had an abortion				0.54	0.59	1.71	0.54	0.59	1.71	0.53	0.59	1.70
Married				−0.29	0.52	0.75	−0.28	0.53	0.75	−0.28	0.53	0.76
Cohabiting				0.01	0.76	1.01	−0.00	0.77	1.00	0.02	0.75	1.02
Employee				0.13	0.44	1.14	0.13	0.44	1.14	0.15	0.44	1.16
Individual level												
Religiosity				−0.02	0.20	0.98	−0.02	0.20	0.98	−0.02	0.20	0.98
Desire a(nother) child				0.24	0.42	1.27	0.25	0.42	1.29	0.25	0.43	1.29
Social level												
Value of motherhood				−0.68	0.44	0.51	−0.68	0.44	0.51	−0.66	0.44	0.51
Parents desire grandchild				0.15	0.38	1.16	0.15	0.38	1.16	0.14	0.38	1.15
Over 40 years old				−0.73	0.41	0.48	−0.74	0.41	0.48	−0.74	0.41	0.48
Enabling conditions												
Education				−0.08	0.09	0.92	−0.08	0.09	0.92	−0.08	0.09	0.92
Family income				−0.06	0.09	0.95	−0.05	0.09	0.95	−0.05	0.09	0.95
White, non-Hispanic				−0.27	0.46	0.77	−0.26	0.46	0.77	−0.25	0.46	0.78
Social Support				−0.97	0.31	0.38**	−0.97	0.31	0.38**	−0.97	0.31	0.38**
Predisposing conditions												
Chronic health condition				−0.03	0.41	0.97	−0.02	0.41	0.98	−0.02	0.41	0.98
General health				−0.59	0.26	0.55	−0.60	0.26	0.55*	−0.60	0.26	0.55*
Cognitive response												
Self-identity as infertile							−0.09	0.55	0.92	0.01	0.67	1.00
Behavioural response												
Sought any medical help										−0.14	0.59	0.87
Constant[a]	−0.989	0.217	0.372***	1.59	1.43	4.89	1.56	1.43	4.78	1.53	1.44	4.60
Nagelkerke R^2			0.07			0.30			0.30			0.30
Model χ^2			11.51*			43.83***			0.03			0.06

Adjusted R^2 P-value is for the change in R^2.
[a]Includes women who are infertile (with intent) in Model 1 and who have the average score on continuous variables (all are mean centred) and the 0 value on dummy variables in Models 2, 3 and 4.
[b]Voluntarily child free had an unrealistic coefficient and was, therefore n removed from the model with an assumption that no cases filled all of the cells.
*$P < 0.05$.
**$P < 0.01$.
***$P < 0.001$.

Discussion

In our total sample of 580, we found that 61% reported FBs and that 28% met the medical definition of infertility (12 months of regular unprotected intercourse without conception) at some point in their lives. In the research on people with infertility who are in treatment, the statement that 15% of people have infertility is so commonly asserted that citations are rarely given to support the statement. These numbers suggest that the majority of research on the coping and adaptation of people with infertility may apply to perhaps half of those who meet the medical definition of infertility and to far fewer of those who suffer from a broader array of FBs.

Our second finding of importance is that the mean CES-D scores for all our FB groups in our analytic sample ($n = 248$) are below the cut-off of 16 for identifying cases of depression. At the same time, there is a higher percentage of women with high scores (23%) among those with FBs than among those

without FBs (16%), and the difference is significant. The 16% in our group without FBs is consistent with two other community surveys that found 14.3% (Knight *et al.*, 1997) and 17.4% (Roberts and Vernon, 2006) above the cut-off of 16. This especially makes sense when we recall that the CES-D scores reflect the respondent's current status. The mean scores for our FB groups ranged from 6.10 to 13.76. We can report two studies that might help to put the relatively low amounts of distress for most of those with FBs in context. Neugebauer *et al.* (1992) reported mean CES-D scores for women who had miscarried. They found that when first interviewed and invited to tell about the miscarriage (at 2 or 6 weeks or even 6 months after the loss), scores were higher (ranging from 18.8 to 23.9) than when the women were later re-interviewed, when their scores were just less than 14. Additionally, a Japanese study of 107 women currently in treatment for infertility reported mean CES-D scores of 13.2, with a

higher mean (15.6) for those experiencing infertility for 4 years or longer and a lower mean (11.0) for those with infertility of less than 4 years duration (Chiba *et al.*, 1997). Our findings and those of Neugebauer *et al.* and Chiba *et al.* suggest that although the emotional impact of FBs may be great at one point in time, the severe distress does not tend to last for the majority of women. This is important clinically because it is common for both women trying to conceive and their spouses to worry that they will never feel normal again. It is not uncommon for male partners to argue that attempts to conceive should be abandoned in order to promote healing. Being able to offer reassurance that healing generally occurs would be quite encouraging, but until we are able to follow these variables prospectively, it will be difficult to know exactly how to interpret these results.

Our finding that self-identify as infertile and sought any medical help explain the higher FSD for the infertile with intent compared with the other FB groups highlights the issue of self-labelling, discussed by Daly (1988). Unsuccessful attempts to conceive are likely to lead to strong negative feelings about the experience (FSD), thus leading to seeking medical help Therefore, the help-seeking group is likely to be more distressed. At the same time, seeking medical evaluation and treatment can lead people to self-identify as infertile, because health-care providers give a name to it (e.g. converting 12 months of sex without conception into infertility). Sometimes labels are helpful and comforting, and sometimes they are not. Greil's (1991) interviews revealed that one strategy for maintaining hope was to consider oneself 'not yet pregnant' rather than 'infertile'. Avoiding the label of infertile was comforting to his participants.

The finding that the miscarriage only group had significantly lower CES-D scores and a lower proportion above the cut-off of 16 than the other fertility problems group is intriguing. Consistent with the group definition, no one in the miscarriage only group self-identified as infertile, and this may explain their lower levels of general distress. In contrast, the other fertility problems group may be the group most stymied about what can be done to meet their family building goals, and this may contribute to the higher levels of general distress (CES-D).

It is interesting to note that demographic and other background characteristics are not very useful in predicting who will be distressed. In contrast, perceived social support appears to lead to lower distress, for both FSD and CED-D distress indicators. This suggests that encouraging patients to maintain or strengthen their social support networks would be helpful. It is ironic then that anecdotal reports from infertility therapists are that women with medical infertility tend to withdraw from family and friends in order to avoid contact with pregnancies and the infants of others–the exact opposite of what may be most therapeutic.

We were surprised that parental status did not help to explain differences in FSD among those with FBs. Although this is counterintuitive, in fact there are a number of reports of similar findings. Both Wright *et al.* (1991) and Domar *et al.* (1992) looked at distress in people in treatment for primary or secondary infertility and found no group differences. A British study looked at differences between women in three

groups: those recruited from assisted reproduction centres, those recruited from adoption agencies and those recruited from surrogacy agencies (van den Akker, 2005). The author found no differences between groups on psychological symptoms, as measured by the General Health Questionnaire, and no differences between those who were mothers and those who were not. This is consistent with our finding that motherhood itself is not related to FSD and yet wanting a child or another child is related to more FSD among those with FBs. If we keep in mind that FSD relates to feeling cheated, feeling guilty, feeling depressed and feeling like a failure as a woman, it is not surprising that current motherhood status is unrelated. These are within-person indicators related more to desire and expectations than actual status in the world. Our data suggest that thinking of one-self as 'infertile now' is a better predictor for FSD than motherhood status.

Our finding that higher levels of income are associated with more FSD is consistent with Scritchfield's (1995) argument that contemporary middle-class White women in America experience infertility as a crisis because they are used to exercising control over their social and physical environments and achieving life goals. Failure to conceive, she argues, is particularly painful for those who have been successful in other aspects of their lives. Although this appears not to be the case when CES-D is used as a measure, it may be valid for FSD.

Consistent with past research, we did find that lower general distress was associated with being over 40 years old, reporting more social support and better general health. In contrast with much of the literature, however, we found that being married was associated with higher CES-D scores. Clinical experience might help explain this anomaly. Being married increases not only a woman's expectations of being able to obtain her desired family size, but also her sense of responsibility to produce for her partner the children he desires. Women who cannot conceive or carry children successfully commonly suggest to their partners that they could marry another to obtain the desired children.

Our data support Greil's (1997) argument that the distress seen in persons with infertility is generally a within-person change rather than the development of a psychiatric syndrome. The experience of FBs may precipitate feelings that seem foreign and may be reported as 'depression', 'anxiety' and 'anger' in such a way that doctors, nurses and therapists operating from a medical model reach for the familiar skills of diagnosis and treatment. From a biopsychosocial perspective, however, our data and that of others support the notion that FBs are better understood as experiences in social contexts rather than as medical conditions. Our data also support the notion of resilience. Not only do we find general distress (CES-D) to be pretty low in this cross-sectional sample and clinically relevant scores only somewhat more common than the general population, but we also find that the mean FSD scores for all the FB groups fall below the midpoint of the possible scores. Taking a long-term perspective on FBs and distress allows us to see that much of this distress may not be permanent and that healing does take place.

This study has some obvious limitations. Because the sample is drawn only from the Midwestern USA, and over-represents

college-educated women, its generalizability is limited. Because it is cross-sectional, we are unable to make causal assertions with any certainty. Whether the self-labelling causes the FSD or vice versa and whether help-seeking results from the distress and the self-labeling or precedes it are important questions we want to try to answer with future research. Prospective data could also help us understand the contributing factors to our finding that women with FBs, especially the infertile with intent group, are more likely to report CES-D symptom scores above the cut-off of 16 than women without FBs. We are currently nearing the end of the first wave of data collection in a national study of persons with FBs. Telephone interviews with approximately 5000 women and their partners, again with an over sample of women of colour, will give us a larger pool of cross-sectional data from which to examine the experiences of persons with FBs. A second wave of data collected 3 years later from women who were childless or who intended more children during wave 1 will allow us to examine these questions of causality regarding distress, self-labelling, and help seeking.

Acknowledgements

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