Social concerns of women undergoing infertility treatment

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Objective: Our study was undertaken to determine [1] what women are disclosing to their employer with regard to their infertility, [2] what demographic characteristics are associated with women who are more likely to disclose, and [3] if there is an association between disclosure and lowering one's stress. We hypothesize that, in certain women, disclosure may lower stress, and therefore increase success rate of in vitro fertilization.
Design: Cross-sectional questionnaire.
Setting: University Infertility Treatment Center.
Patient(s): We handed out a questionnaire to patients being evaluated and treated for infertility over a 6-month period. A total of 267 questionnaires were handed out and all were collected.
Main Outcome Measure(s): We collected demographic data as well as information regarding privacy, disclosure, and stress. We then compared women who disclose to their employer that they are being seen by an infertility specialist to those women who do not disclose. We also measured stress and determined if higher stress level was associated with disclosure or nondisclosure.
Result(s): Most women who did disclose did so because they needed a reason to leave work for frequent doctor visits. Among women who did not disclose, the main reason for nondisclosure was to protect their privacy. Women with a high school education were more likely to disclose compared with those with a college and postgraduate education. African American/Caribbean American women were least likely to disclose. Those who were out of work more often because of their infertility were more likely to disclose. There was not an association with disclosure and decreasing stress level.
Conclusion(s): Women who did or did not disclose their infertility status to their employer were different with regard to level of education, race/ethnicity, and number of visits per month to the doctor. The decision to disclose does not seem to have a significant impact on stress. (Fertil Steril® 2007;88:817–21. ©2007 by American Society for Reproductive Medicine.)

Key Words: Stress, privacy, disclosure, infertility

In 1998, the Supreme Court of the United States of America ruled that reproduction is a "major life activity" covered under the Americans with Disabilities Act (1). Since then, the Family Building Act was put into legislation (2), which provides insurance coverage for women undergoing treatment for infertility. The state of New Jersey is one of 13 states in the United States that currently provides mandatory insurance coverage for infertility treatment. In another two states insurance coverage is not mandatory; however, companies are required to offer coverage for infertility treatment. The mandate includes coverage for up to four egg retrievals in women younger than 45 years of age. These mandates verify that federal and local governments are supporting women undergoing treatment for infertility.

Women being treated or evaluated for infertility must have a flexible work schedule and be willing and able to go for frequent office visits. This can lead to hours and sometimes days missed at work. If an employer is not supportive of these frequent absences, the situation can lead to increased stress levels, which in turn, can affect fertility. Research suggests that stress, depression, anxiety, and other negative psychologic feelings result in poorer outcomes for patients undergoing IVF (3–6).

Women treated for infertility have many social concerns with regard to their infertility. There also can be profound emotional stress as a result of infertility (7). One of the more controversial issues for many couples concerns privacy and disclosure with respect to their infertility and/or

Received August 5, 2006; revised and accepted December 29, 2006.
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0015-0282/07/$32.00
doi:10.1016/j.fertnstert.2007.01.009

infertility treatments. This study was designed to investigate some of these social concerns. Our objectives were as follows: [1] to determine what women disclose to their employers, [2] to compare women who do disclose their infertility to their employer with women who do not disclose, and [3] to evaluate if there is an association between reported stress and the decision to either disclose or not to disclose infertility treatment. We hypothesize that certain women could lower their stress by disclosing that they are currently being treated for infertility, and by doing so, they may improve their outcomes of infertility treatment.

MATERIALS AND METHODS

Internal review board approval was obtained for this study. All patients who presented to the University Center for Reproductive Endocrinology and Fertility at UMDNJ–Robert Wood Johnson Medical School, New Jersey, for a 6-month period (April to September 2004) were invited to participate and complete our questionnaire. The questionnaire consisted of 38 questions, and was designed to take approximately 10 minutes. Patients were asked to complete the questionnaire while waiting for the doctor. All surveys handed out were collected from each patient as they were called into the doctor's office. The survey was given to women who sought first-time evaluation for infertility as well as those who were currently undergoing treatment.

The survey contained questions regarding demographic data, including age, years with partner, education (high school, college, postgraduate), race/ethnicity (Caucasian, African American/Caribbean American, Asian, other), and religion (Christian, Hindu/Buddhist, Jewish, other). Questions addressing employment satisfaction, freedom to leave work for frequent doctor visits, reproductive history, infertility treatments, as well as questions on disclosure and perceived level of support were included in the questionnaire. Finally, the questionnaire included questions regarding stress level and privacy considerations.

Included in the survey was a validated global measure of stress known as the Perceived Stress Scale (8). The original scale is a 14-item instrument; however Cohen et al (8) proved the reliability and validity of a four-item version, which was used in this study.

Satisfaction with employment as well as freedom to come and go from work was assessed. Scores were assigned on a 1 to 7 scale, with 1 being equivalent to "not satisfied," 3 to "slightly satisfied," 5 to "moderately satisfied," and 7 to "very satisfied." A similar scoring pattern was assigned to freedom to come and go from work, with 1 being equivalent to "no freedom," 3 to "some freedom," 5 to "moderate freedom," and 7 to "total freedom."

Continuous variables such as patient's age, Perceived Stress Scale scores, and so on, were analyzed using mean and SD. The Student's *t* test was used to examine differences in characteristics between women who did and did not disclose their infertility status. Interval data such as gravidity, parity, and number of people disclosed were analyzed as proportion of total subjects who responded to the survey. A chi-square test was applied to compare differences in proportions between women who did and did not disclose their infertility status, and evaluated associations based on odds ratio (OR) with a 95% confidence interval (CI). All tests of hypothesis were two tailed, with a type 1 error rate set at 5%. Incomplete surveys were not analyzed.

RESULTS

A total of 267 questionnaires were handed out and collected. They were divided into groups based on whether the patient did or did not disclose to their employer that they were undergoing treatment for infertility. Forty-three percent (114 of 267) of the women surveyed did not disclose, 32% (85 of 267) did disclose, 12% (33 of 267) surveyed stated disclosure was not applicable (i.e., they were either unemployed, homemakers, or were self-employed), and 12% (35 of 267) were incomplete surveys. Therefore, there were 199 subjects in whom analysis could be conducted to compare women who disclose and women who do not disclose, excluding those in which disclosure was not applicable and the incomplete surveys.

Subjects were asked for their reasons for disclosure or nondisclosure, and were permitted to give more than one reason. Analysis of the 114 subjects who did not disclose revealed that over four fifths (82%; 94 of 114) indicated the reason was because they were protecting their privacy, 25% (28 of 114) were protecting the privacy of their spouse, 18% (20 of 114) were worried disclosing would hurt their chance of promotion, 10% (11 of 114) did not want special treatment, and 7% (8 of 114) were embarrassed. Among women that disclosed to their employer, 79% (67 of 85) did so because they needed to leave work for infertility-related appointments, 45% (38 of 85) disclosed because they had a close relationship with their employer, 41% (35 of 85) had nothing to hide, and 8% (7 of 85) desired additional support.

We considered whether there was a correlation between education and disclosure. Of the 199 surveys analyzed 1 subject did not answer the question regarding level of education, 18 were high school educated, 106 were college educated, and 74 were postgraduate educated. For the women in whom the highest level of education was high school, 72% (13 of 18) disclosed, for those respondents who attended college, 44% (47 of 106) disclosed, and for those who completed postgraduate education, 32% (24 of 74) disclosed. This difference was statistically significant (P=.008) (Table 1).

The difference in race/ethnicity between those who disclose and those who did not disclose revealed that among Caucasian women, 46% (48 of 105) did disclose, whereas among African/Caribbean American women, the disclosure rate was 24% (8 of 33) (Table 1). Two subjects did not answer this question.

TABLE 1

Disclosure versus nondisclosure in each group and the correlation.

	Disclose	Nondisclose	*P* value
Education (nonresponders N = 1)			
High school	13/18 (72%)	5/18 (28%)	
College	47/106 (44%)	59/106 (56%)	
Postgraduate	24/74 (32%)	50/74 (68%)	.008
Race/ethnicity (nonresponders N = 2)			
Caucasian	48/105 (46%)	57/105 (54%)	
African/Caribbean American	8/33 (24%)	25/33 (76%)	
Asian	16/36 (44%)	20/36 (56%)	
Other	12/23 (52%)	11/23 (48%)	.1
Religion (nonresponders N = 0)			
Christian	48/104 (46%)	56/104 (54%)	
Hindu/Buddhist	8/16 (50%)	8/16 (50%)	
Jewish	5/16 (31%)	11/16 (69%)	
Other	24/63 (38%)	39/63 (62%)	.5
Pregnancy loss (nonresponders N = 0)			
Previous loss	57/139 (41%)	82/139 (59%)	
No loss	28/60 (47%)	32/60 (53%)	.5
First visit to infertility specialist (nonresponders N = 1)			
No	54/106 (51%)	52/106 (49%)	
Yes	30/92 (33%)	62/92 (67%)	.009
Days out of work because of infertility evaluation or treatment (nonresponders N = 37)			
0–3 days/month	45/115 (39%)	70/115 (61%)	
4–6 days/month	16/27 (59%)	11/27 (41%)	
>7 days/month	12/20 (60%)	8/20 (40%)	.06
Sex of supervisor (nonresponders N = 4)			
Female	52/105 (50%)	53/105 (50%)	
Male	33/90 (37%)	57/90 (63%)	.07
Stress about infertility (nonresponders N = 18)			
Not at all	4/13 (31%)	9/13 (69%)	
Mildly	17/44 (39%)	27/44 (61%)	
Moderately	37/86 (43%)	49/86 (57%)	
Very stressed	21/38 (55%)	17/38 (45%)	.3

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Women who were seeing the fertility doctor for the first time were less likely to disclose to their employer compared with those women who had been to the fertility specialist more than once (P=.009) (Table 1). Analysis of the respondents' answer to a question regarding the number of days missed from work per month revealed that 39% (45 of 115) of those who missed 0 to 3 days per month did disclose, 59% (16 of 27) of those who missed 4 to 6 days per month did disclose, and 60% (12 of 20) of those who missed 7 or more days per month did disclose. This difference approached statistical significance (P=.06) (Table 1). There were 37 respondents who did not answer this question.

We analyzed our data for ORs and found high school educated women were over nine times as likely to disclose compared with those with a postgraduate level of education (OR 9.7, 95% CI 2.59, 36.25). Compared with African/Caribbean American women, Caucasian women were 3.8 times as likely to disclose (95% CI 1.31, 11.08), and Asian/Indian women were almost five times as likely to disclose (95% CI 1.35, 16.35). Women who were out of work for >7 days per month were 4.2 times as likely to disclose when compared with those who were out of work for 0 to 3 days per month (95% CI 1.17, 14.84). Finally, respondents with a female supervisor were two times as likely to disclose compared with those with a male supervisor; however, this was not statistically significant (95% CI 0.27, 1.06).

We used two different methods to analyze stress in those who disclose and those who do not disclose. We compared these groups with regard to their own assessment of stress

TABLE 2

Comparison of age, satisfaction at work, freedom at work, and global stress scale for those who disclose versus those who do not disclose.

	Disclose	Nondisclose	
Patient's age—mean (SD)	34.5 (4.3)	34.4 (5.6)	$P=.9$
Satisfaction at work—median (range)	5 (1–7)	5 (1–7)	$P=.2$
Freedom at work—median (range)	5 (1–7)	5 (1–7)	$P=.4$
Perceived stress scale score—mean	6.1	6.7	$P=.2$

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level and found there to be no differences between stress levels and disclosure (Table 1). We also found there to be no difference between those who disclose and those who do not disclose when the comparison was based on the results of the Perceived Stress Scale (Table 2).

DISCUSSION

The demands on infertile couples can be great. Current treatment regiments can be very time consuming, and frequent office visits are mandatory. For working women, this necessitates understanding, flexibility, and cooperation at the workplace from co-workers and supervisors, which would require in some instances disclosing ones infertility. Stress has been shown to affect the outcomes of infertility treatment, and it was our hypothesis that some patients may lower their stress by disclosing their problems with fertility, whereas others may benefit from not disclosing. However, results of this survey suggest that disclosure of one's infertility status is not a significant factor in either increasing or diminishing personal stress. Hence, the decision to disclose must reflect the values and decisions of each women and her partner; it appears to have little implications for treatment.

There was an association between disclosure and number of days away from work. The more time spent away from work, the more likely a woman was to disclose that she was undergoing treatment and or evaluation for infertility. This is not surprising, considering that most of women who elected to disclose their infertility did so because they needed to leave work for appointments. There were a large number of respondents who did not answer this question, possible because of the fact that for many of these women it may have been the first time being evaluated for infertility and they felt the question was not applicable. When we analyzed this data including the nonresponders we got a *P* value of .05, indicating that there still was an association between disclosure and number of days away from work.

The overwhelming majority of women who did not disclose were protecting their privacy. Of the women who chose not to disclose, almost 20% indicated they were worried their chances of promotion would be hindered by the knowledge that they were being treated for infertility. This finding is particularly significant because fears regarding career advancement can only lead to increased stress. These women may believe that the knowledge of their infertility may be viewed as a weakness; they may believe their supervisor would realize how demanding these treatments are and therefore not consider them for a promotion; or they may believe their supervisor would think ahead at the prospect of a successful pregnancy and extended leave of absence during and after the pregnancy and therefore not consider them for promotion.

There was no difference between subjects who disclosed and those who did not disclose with regard to age, length of time with partner, satisfaction at work, freedom to come and go from work, if they had a previous pregnancy loss or not, and religion. Some of the religious categories contained very few women; however, when looking at each group there were no differences with regard to disclosure versus nondisclosure.

There was a significant correlation between education and disclosure. Women with a higher educational status were less likely to disclose their infertility status. In part, this may be a function of the fact that these women had higher positions that permitted more flexible scheduling, and therefore they did not need to disclose in order to leave work for doctor visits. It would be interesting to further investigate this data and its association with the aforementioned findings that one out of five women did not disclose because they are worried that it would hurt their chance of promotion. In other words, are the women with higher education less likely to disclose because they are the ones worried about being penalized at work for their infertility status? There are many confounding factors regarding level of education, and we would be hesitant to draw many conclusions from this data; however, it is an interesting finding that we would like to pursue with further research.

With respect to ethnicity, African America/Caribbean American women were least likely to disclose their infertility status. There may be confounding factors, such as level of education, and location where this study was conducted. There may also be cultural differences with respect to maintaining privacy.

An interesting finding of our study was that women were more likely to disclose their infertility status to their

supervisor if their supervisor was a female. This may be because women have a greater comfort level with other women when discussing infertility. This difference approached statistical significance, and we believe that further study in this area is warranted.

There was no difference in stress scores and disclosure. Although there are many sources of stress for women undergoing infertility treatment, the decision to disclose or keep private one's infertility status and treatments from one's employer does not appear to be a significant stress-enhancing consideration.

We are not able to determine how many patients refused to participate in our study. We attempted to limit this bias by our study design in that every questionnaire given out was collected before seeing the doctor; however, there were many questionnaires that were incomplete. We do not know if these were incomplete because subjects refused to participate in the study, or they did not have enough time to complete the survey. Because we are unable to determine who refused to participate versus those who did not have enough time, we are not able to identify any differences between those who did and did not want to participate in our study.

There are many factors that could confound this data, and in a survey it is particularly difficult to control for the psychologic, behavioral, and social differences between these groups. However, some of the differences noted in this study may help to direct future work in this area.

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