2010

The Hidden Infertile: Infertile Women without Pregnancy Intent in the United States

Arthur L. Greil
Alfred University

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

Katherine Johnson
Pennsylvania State University University Park

Kathleen Slauson-Blevins
University of Nebraska-Lincoln

Karina M. Shreffler
Oklahoma State University

Published in final edited form as:
Fertil Steril. 2010 April ; 93(6): 2080–2083. doi:10.1016/j.fertnstert.2009.08.024.

The Hidden Infertile: Infertile Women without Pregnancy Intent in the United States*

Arthur L. Greil, Ph.D. [Professor of Sociology],
Alfred University Alfred, New York

Julia McQuillan, Ph.D. [Associate Professor of Sociology],
The University of Nebraska at Lincoln Lincoln, Nebraska jmcquillan2@unlnotes.unl.edu

Katherine Johnson, M.A. [Doctoral Candidate],
The Pennsylvania State University University Park, Pennsylvania kmj165@psu.edu

Katherine Slauson, M.A. [Doctoral candidate], and
The University of Nebraska at Lincoln Lincoln, Nebraska kslauson@unlserve.unl.edu

Karina M. Shreffler, Ph.D. [Assistant Professor in Human Development and Family Science]
Oklahoma State University Tulsa, Oklahoma karina.shreffler@okstate.edu

Abstract

A national probability sample reveals two relatively distinct groups of infertile women: those with intent, who have experienced a period of 12 or more months during which they tried to conceive but did not, and those without intent, who had a period of at least 12 months during which they could have conceived and did not but who do not describe themselves as having tried to become pregnant at that time. Those with intent are more likely to identify as having a fertility problem, to be distressed, and to pursue infertility treatment than those without intent, suggesting that many women do not realize that they meet the medical criteria for infertility and may therefore wait longer to get help, therefore lowering their chances of conception.

According to commonly accepted medical criteria for infertility, women are categorized as infertile if they experience a year of unprotected intercourse without conception.[1] Using this definition, the National Survey of Family Growth (NSFG) estimates that 7.4 percent of married U.S. women were infertile in 2002.[2] It makes no explicit reference to intent to conceive, but, given the availability of contraception, this definition implies that women meeting the criteria for infertility were ***trying*** to conceive. Data from the National Study of Fertility Barriers (NSFB), a probability-based sample of 4,712 U.S. women, reveal that there are a large number of women who at some point in their lives fit the NSFG definition of infertility but who do not describe themselves as having ***tried*** to become pregnant at that time. Because women who meet the criteria but are not trying to get pregnant are less likely to go to fertility clinics, they are

*This research was supported in part by grant R01-HD044144 “Infertility: Pathways and Psychosocial Outcomes” funded by NICHD. Dr. Lynn White (The University of Nebraska-Lincoln) and Dr. David R. Johnson (The Pennsylvania State University) were Co-PIs on the first wave of data collection.

For more information, contact: Arthur L. Greil, Department of Sociology, Alfred University, 1 Saxon Drive, Alfred, NY 14802. Phone: 607-871-2885. Fax: 607-871-2085. fgreil@alfred.edu.

much less likely to be studied in infertility research. We therefore call these women the "hidden infertile". Drawing attention to the "hidden infertile" adds texture to our understanding of the experience of infertile women and sheds light on the following paradox: why, if infertility is as distressing as is often reported, do so many infertile women not pursue treatment?

Studies of infertile women and involuntary childlessness[3-7] usually describe infertility as an extremely distressing experience, characterized by a spoiled identity and a feeling that one's life course has been interrupted. Despite such strong evidence that infertility is distressing, only about half of women who fit the criteria for infertility seek treatment.[2, 8, 9]This apparent paradox may be explained in part by the limitations of many samples used to study the psychosocial consequences of infertility. Most studies of women's responses to infertility have focused on treatment-seekers at infertility clinics connected with research hospitals and therefore ignore the experience of about half of the female infertile population.[4] Women who seek treatment are likely to differ from those who do not seek help. We suggest that intent to conceive at the time of the episode is an important – and under studied - fundamental difference between those not seeking medical help and those seeking medical help for infertility.

In the common-sense view implicit in the medical definition, women who do not want to become pregnant use contraception, and women who want to become pregnant do not take contraception. This view implies that women who do not use contraception consistently give evidence that they are trying to become pregnant. But women do not always use contraception consistently and efficiently. Furthermore, there are women who, for religious or other reasons, are reluctant to say that they are trying to get pregnant but who are also unwilling to try to prevent conception. Such women do not state an intent to conceive, but could easily meet the medical criterion for infertility if they have intercourse for a year without protection or conception. Many U.S. women are, at some points in their lives, not trying to or trying not to conceive, but are "okay either way."[10] Recent research has pointed to the importance of self-definition as infertile as a key feature in the helpseeking process. 9, 11, 12. As a pragmatic solution to an unexpected conundrum in population based research, Greil and McQuillan [9]divided women meeting the criteria for infertility into the "infertile with intent" (women who say they tried to conceive for at least 12 months without conception) and the "infertile without intent" (women who report having had unprotected intercourse without conception but who do not say that they were consciously trying to conceive at the time). In this article we compare the infertile with intent to the infertile without intent and demonstrate that the two groups differ from one another with regard to both helpseeking behavior and fertility-specific distress.

Our data come from the National Survey of Fertility Barriers (NSFB), a nationally representative random-digit-dialing telephone survey designed to study infertility. This dataset is available at: http://sodapop.pop.psu.edu/data-collections/nsfb. Institutional Review Board approval was obtained at the two university study sites prior to data collection. Our sample includes 2,286 women ages 25-45 who reported that they had unsuccessfully tried for a year or more to get pregnant or that had ever had regular unprotected sex for a year or more without getting pregnant. The sample was split almost evenly between women with intent 51.3% and women without intent 48.7%.

We examined the differences between women with or without intent at the time of their infertility episode across a wide range of characteristics. For categorical variables, we used chi-square tests to assess significant differences between the two groups of women. For continuous variables, we used independent samples t-tests to compare means of both groups. Table 1 displays results showing differences between women with and without intent across study variables. There were a number of statistically significant differences between the groups, suggesting that women meeting criteria for infertility with or without intent can be meaningfully described as distinct.

Women who had intent were more likely to self identify as having a fertility problem (57.6% compared to 18.4%) and to say that they would like a(nother) baby (47.6% compared to 36.3%) compared to women without intent. More women who had intent had had an episode within the last five years (27.5% compared to 20.1%). The distributions by race differed somewhat, with a larger percentage of Black women without intent and a larger percentage of Hispanic women with intent. Infertility type differed across the two groups of women: more women who had intent had experienced primary infertility (45.4% compared to 2.6% of infertile without intent) whereas more women without intent had experienced either secondary infertility (89.7% compared to 50.9% for infertile with intent) or secondary infertility that did not result in a live birth (7.6% compared to 3.7%). Women who had intent were also more likely to be married (69.1% compared to 55.4% for without intent).

A greater percentage of women who had intent reported chronic health conditions (30% compared to 23.7%) and lived in a state with mandated infertility insurance coverage (48.5% compared to 44%). More women without intent reported not having any health insurance (18% compared to 14.8%). Compared to women without intent, women with intent experience greater social pressure to have a child across nearly all indicators. For example, women with intent were more likely to report that their partner wanted a(nother) baby (39.4% compared to 27.1%) and that having a baby was very important to their partner (35.9% compared to 25.4%) and to their parents (27.9% compared to 22.8%). They were also more likely to report that they had friends who had pursued infertility treatment (49.3% compared to 40.2%) and that they were encouraged to seek treatment by their family (29.8% compared to 3.5%) and their partner (31.9% compared to 4.9%).

Women who had intent were more like to pursue infertility treatment. They were more likely to consider treatment (63.2% compared to 11.8%), to talk to a doctor about infertility (49.8% compared to 7.1%), to have tests (39.3% compared to 3.3%), to receive treatment for infertility (26.5% compared to 1.3%), and to receive ART treatment (5.5% compared to .2%). Women with intent had higher family incomes than women without intent ($54,840 compared to $47,656) but lower scores on the social support scale (M=3.42 compared to M=3.58). The intent group scored higher on their perceived importance of motherhood (M=3.47) than the no intent group (M=3.30), and higher on the fertility-specific distress (.39) than the no intent group (M=.14).

Our results document the existence of two relatively distinct groups of infertile women: those with intent who report trying to conceiving during their episode and those without intent who had a similar period of 12 or more months during which they had unprotected intercourse, but were not trying to conceive. Women meeting the criteria for infertility with intent are more likely to have experienced an episode of infertility in the recent past, to have primary infertility, to self-identify as infertile, to be married, to have higher family incomes, to have higher levels of education, to have private health insurance, to have more social pressure to pursue infertility treatment, to actually pursue treatment, and to have higher levels of fertility specific distress than women without intent.

These results suggest caution about generalizing from clinic-based samples of treatment-seekers, because we will miss the distinct experiences of the “hidden infertile”. Including non-treatment seekers in research on infertility is essential to fully understanding the infertility helpseeking process. Recognizing that intent is essential to understanding infertility allows us to better grasp the wide range of medical help-seeking and emotional responses to infertility, and will help to disentangle the effects of infertility and infertility helpseeking on distress.

Our research raises questions about the meaning of not seeking medical help for infertility. Do the half of women who meet the criteria for infertility but do not seek help represent unmet

need, or do they represent women who are content to accept their situation because they do not have a purposive approach to pregnancy? Why do women have unprotected intercourse for at least 12 months if they are not trying to conceive? Are there religious, health access, or relationship characteristics that explain differences in intent and behavior? We need greater understanding of the ***meaning*** of twelve months of unprotected intercourse without conception to women in order to understand women's responses to infertility episodes. The medical conditions that lead to an inability to conceive may only become a "medical" problem when women intend pregnancy and not before then. It is also possible that some women in our sample have ceased trying to conceive because they do not know that they have medical options. These results raise important questions about the role of pregnancy intent in defining and understanding the experience of infertility. They also demonstrate the need to determine how aware women are that they meet the criteria for infertility and that they could get help if they so desire.

References

1. Sciarra J. Infertility - an International Health Problem. Int J of Gynecol & Obstet Aug;1994 46(2):155–163.
2. Stephen EH, Chandra A. Declining Estimates of Infertility in the United States: 1982-2002. Ferti Steril 2006;86(3):516–523.
3. Becker, G. The Elusive Embryo: How Women and Men Approach New Reproductive Technologies. University of California Press; Berkeley: 2000.
4. Greil AL. Infertility and psychological distress: a critical review of the literature. Soc Sci Med 1997;45 (11):1679–1704. [PubMed: 9428088]
5. Henning, K.; Strauss, B. Psychological and Psychosomatic Aspects of Involuntary Childlessness: State of Research at the End of the 1990s. Hogrefe and Huber Publishers; Ashland, OH: 2002.
6. Johansson M, Berg M. Women's experiences of childlessness 2 years after the end of in vitro fertilization treatment. Scand J Caring Sci Mar;2005 19(1):58–63. [PubMed: 15737167]
7. McQuillan J, Greil AL, White L, Jacob MC. Frustrated fertility: Infertility and psychological distress among women. J Marr Fam Nov;2003 65(4):1007–1018.
8. Boivin J, Bunting L, Collins JA, Nygren KG. International Estimates of Infertility Prevalence and Treatment-Seeking: Potential Need and Demand for Infertility Medical Care. Hum Reprod 2007;22 (6):1506–1560. [PubMed: 17376819]
9. Greil AL, McQuillan J. Help-seeking patterns among subfecund women. J Reprod Infant Psych Nov; 2004 22(4):305–319.
10. Greil, AL.; McQuillan, J. Exploring the Ambiguities of Assigning Fertility Status; Paper presented at: Reproductive Disruptions; Ann Arbor, MI. 2005;
11. Bunting L, Boivin J. Decision-Making about Seeking Medical Advice in an Internet Sample of Women Trying to Get Pregnant. Hum Reprod 2007;22:1662–1668. [PubMed: 17416917]
12. White L, McQuillan J, Greil AL, Johnson DR. Infertility: Testing a helpseeking model. Soc Sci & Med Feb;2006 62(4):1031–1041. [PubMed: 16360257]

Table 1

Descriptives by infertilityity type (*National Survey of Fertility Barriers, weighted*)

Categorical Variables	Subfecund with Intent (n = 1045)	Subfecund without Intent (n = 1117)	
Infertility Type			
Primary Infertility	45.4%	2.6%	***
No Live Birth	3.7%	7.6%	***
Secondary	50.9%	89.7%	***
Identity Issues			
Thinks has fertility problem	57.6%	18.4%	***
Would like [a/nother] baby	47.6%	36.3%	***
Importance of leisure	43.0%	43.8%	
Importance of work	51.7%	53.6%	
Social pressure			
Partner wants more	39.4%	27.1%	***
Very important to partner	35.9%	25.4%	***
Very important to grandparents	27.9%	22.8%	**
Most/all friends and family have ki	85.1%	82.7%	
Friends pursue	49.3%	40.2%	***
Family encourages	29.8%	3.5%	***
Partner encourages	31.9%	4.9%	***
Helpseeking			
Considered treatment	63.2%	11.8%	***
Talked to a doctor	49.8%	7.1%	***
Had tests	39.3%	3.3%	***
Had treatment	26.5%	1.3%	***
Had ART	5.5%	0.2%	***
Background Characteristics			
Episode timing			
First episode within 5 years	27.5%	20.1%	***
First episode 6-10 years	26.7%	24.5%	
First episode >10 years	53.7%	55.8%	
Race			
White	55.6%	54.4%	
Black	16.4%	23.6%	***
Hispanic	21.0%	16.9%	*
Asian	7.0%	5.1%	
Social Roles			
Married	69.1%	55.4%	***
Cohabiting	2.1%	0.9%	*
Never Married	10.3%	25.1%	***
Employee (Full or Part Time)	63.3%	66.0%	

Categorical Variables	**Subfecund with Intent (n = 1045)**	**Subfecund without Intent (n = 1117)**	
Health-related			
Chronic health condition	30.0%	23.7%	***
Private Health insurance	61.0%	59.2%	
Public health insurance	19.8%	19.0%	
No health insurance	14.8%	18.0%	*
Other health insurance	4.4%	3.7%	
State coverage	48.5%	44.0%	*
No regular doctor	15.2%	18.1%	
Continuous Variables	***Mean (SD)***	***Mean (SD)***	
Fertility-specific distress	.39 (.28)	.14 (.16)	***
Importance of motherhood	3.47 (.50)	3.30 (.58)	***
Family Income	54,840 (39,777)	47,656 (33,877)	***
Social support	3.42 (.80)	3.58 (.68)	***
Age (25-45)	36.08 (5.78)	35.84 (6.10)	
Education (years)	13.14 (3.20)	13.21 (2.48)	
Economic hardship	1.76 (.89)	1.73 (.80)	
Self-rated health	2.96 (.79)	2.99 (.70)	
Internal medical locus of control	2.98 (0.52)	2.99 (0.50)	
Perceived stigma of fertility proble	2.72 (0.62)	2.69 (0.59)	
Ethical concerns about infertility tr	1.59 (.55)	1.55 (.53)	
Traditional gender ideology	1.94 (.53)	1.94 (.54)	
Attitude toward medical care	3.31 (0.50)	3.31 (0.50)	

Note : Chi-square tests were performed for categorical variables. Independent samples t tests were performed for continuous variables.

* p<.05;

** p<.01;

*** p<.001.