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#### **ORIGINAL ARTICLE Infertility**

# Age shock: misperceptions of the impact of age on fertility before and after IVF in women who conceived after age 40

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**STUDY QUESTION:** What do older women understand of the relationship between age and fertility prior and subsequent to delivering their first child?

**SUMMARY ANSWER:** Women who were first-time parents over the age of 40 did not accurately perceive the relationship between age and fertility prior to conceiving with IVF.

**WHAT IS KNOWN ALREADY:** While increases in women's age at their first birth have been most pronounced in relatively older women, the rapidity of fertility decline is not appreciated by most non-infertility specialist physicians, the general public or men and women who are delaying childbearing.

**STUDY DESIGN, SIZE AND DURATION:** Qualitative retrospective interviews were conducted from 2009 to 2011 with 61 self-selected women who were patients in one of two fertility clinics in the USA.

**PARTICIPANTS/MATERIALS, SETTING, METHODS:** All participants had delivered their first child following IVF when the woman was 40 years or older. The data include women's responses to the semi-structured and open-ended interview questions 'What information did you have about fertility and age before you started trying to get pregnant?' and 'What did you learn once you proceeded with fertility treatment?'

**MAIN RESULTS AND THE ROLE OF CHANCE:** Of the women, 30% expected their fertility to decline gradually until menopause at around 50 years and 31% reported that they expected to get pregnant without difficulty at the age of 40. Reasons for a mistaken belief in robust fertility included recollections of persistent and ongoing messaging about pregnancy prevention starting in adolescence (23%), healthy lifestyle and family history of fertility (26%), and incorrect information from friends, physicians or misleading media reports of pregnancies in older celebrity women (28%). Participants had not anticipated the possibility that they would need IVF to conceive with 44% reporting being 'shocked' and 'alarmed' to discover that their understanding of the rapidity of age-related reproductive decline was inaccurate'. In retrospect, their belated recognition of the effect of age on fertility led 72% of the women to state that they felt 'lucky' or had 'beaten the odds' in successfully conceiving after IVF. Of the women, 28% advocated better fertility education earlier in life and 23% indicated that with more information about declining fertility, they might have attempted conception at an earlier age. Yet 46% of women acknowledged that even if they had possessed better information, their life circumstances would not have permitted them to begin childbearing earlier.

**LIMITATIONS AND REASONS FOR CAUTION:** Both the self-selected nature of recruitment and the retrospective design can result in biases due to memory limitations or participant assimilation and/or contrast of past events with current moods. The cohort did not reflect broad homogeneity in that the participants were much more likely to be highly educated, Caucasian and better able to pay for treatment than national population norms. As attitudes of older women who were unsuccessful after attempting IVF in their late 30s or early 40s are not represented, it is possible (if not likely) that the recollections of women who did not conceive after IVF would have been more strongly influenced by feelings of regret or efforts to deflect blame for their inability to conceive.

**WIDER IMPLICATIONS OF THE FINDINGS:** While the failure to appreciate the true biological relationship between aging and fertility may be common and may reflect inaccessibility or misinterpretation of information, it is not sufficient to explain the decades-long socio-demographic phenomenon of delayed childbearing.

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Key words: age-related infertility / IVF / delayed parenting / fertility information

## Introduction

Data from the most recent CDC National Survey of Family Growth indicate that infertility is a significant health concern that affects 11.8% of all reproductive age women in the USA (Chandra et al., 2005). Much of this often-publicized 'infertility epidemic' has long been attributed to the phenomenon of delayed childbearing (Aral and Cates, 1983). An increase in a woman's age at her first birth has occurred across all age groups but has been most pronounced in relatively older women, such that one out of every five American women has her first child after the age of 35, an 8-fold increase over the previous generation (Matthews and Hamilton, 2009). This dramatic demographic shift toward delayed conception has been accompanied by a 50-fold increase in the annual number of IVF procedures performed in the US since 1985, half of which are currently performed on women over age 35 (SART, 2009). While the chance of a live birth after a cycle of IVF plummets from 41% at age 35 to 4% after age 42 (SART, 2009), the rapidity of this fertility decline is not appreciated by most non-infertility specialist physicians, the general public or men and women who are delaying childbearing (Bertarelli Foundation Scientific Board, 2000; Hammond et al., 2002; Hewlett, 2002; Tough et al., 2006, 2007; Maheshwari et al., 2008; Bretherick et al., 2010; Balasch and Gratacós, 2011; Daniluk et al., 2012), and the tension between biological imperatives and women's socio-cultural aspirations continues to be a theme in the popular media (Slaughter, 2012).

In a larger interview-based qualitative study addressing the experience of women who became first-time parents after age 40 using IVF, we were surprised to find that many participants were aware of the general effects of age on fertility, yet they were 'shocked' when they discovered the magnitude of their personal risk of age-related infertility (Mac Dougall *et al.*, 2012). This paper is part of that larger study, but is focused specifically on the question of infertile women approaching age 40 and their understanding of the relationship between age and fertility before and after successfully undergoing IVF.

## Methods

The entire study, featuring qualitative exploratory research on the experiences of later-life parenting after assisted reproduction, was approved by the institutional review board at the University of California, San Francisco. Respondents were recruited through two IVF centers in Northern California. Practitioners sent letters to former female patients who had used IVF to successfully conceive their first child and were age 40 or older at the time of delivery. Those interested sent a postcard to the investigators stating their willingness to consider participation. From 2009 to 2011, researchers trained in qualitative interview methods (Morse and Field, 1995; Hammersley and Atkinson, 2007) interviewed 46 couples and 15 individuals, a number considered to be manageable for the collection and analysis of in-depth, qualitative data (Langness and Frank, 1981). All participants reviewed and signed informed consent documents prior to being interviewed. Because this paper addresses women's retrospective understanding of age-related fertility, it is based on the interview responses of only the female participants. One- to 2-h long interviews were semistructured with a total of 55 open-ended questions that focused on how decisions about later parenting and use of reproductive technology were made and how stances toward age emerged. Questions were developed from pilot data derived from a previous study of older IVF patients who had subsequently conceived using donated oocytes (Friese *et al.*, 2006). Demographic data were collected and interviews were recorded and transcribed verbatim.

An in-depth process of code development took place (Strauss and Corbin, 1990; Luborsky, 1994; Mays and Pope, 2000) in which codes were developed and successive phases of trial coding were conducted until pairs of coders reached a high level of agreement (Mays and Pope, 1995; Pope et al., 2000). The entire data set was then coded using Atlas.ti, a qualitative data analysis program (Muhr, 1993-2011). The findings in this article contain an analysis of the code 'Info/Age Prior' defined as 'discussion of any knowledge about the effect of age on fertility (when they knew, what they knew) prior to ART process' and the code 'Info/ Age Post' defined as 'discussion of any knowledge about the effect of age on fertility learned during the ART process, learned from the clinic or from other sources'. The data include responses to the interview questions 'What information did you have about fertility and age before you started trying to get pregnant?' and 'What did you learn once you proceeded with fertility treatment?', as well as any ad hoc discussion of these topics. Secondary themes were identified from these initial codes and quantified for this analysis. As these questions were semi-structured and open-ended, not all women addressed the major themes, while others referenced more than one theme in their response.

## Results

There were 61 families who participated in the study. These families were composed of 51 heterosexual couples, 4 lesbian couples and 6 single women. This paper includes data from the 61 women who conceived and delivered children after age 40. The attrition rate between the first and the second interviews was 2%. The women's median age at the birth of their first child was 42 years. The majority of participants were Caucasian, employed, married and identified as a member of a religious group, had a post-graduate education and reported median family incomes between \$150 000 and \$199 000.

The median number of IVF cycles was two (range: 1–6). All the families had at least one live birth as the result of undergoing IVF. The median number of living children via IVF was one and the median age of children resulting from IVF was 3.5 years (range <1-10). Approximately 75% of all families had used their own gametes for conception via IVF, 15% had used donor sperm and 10% used donor oocytes or both to conceive one or more children. These data are detailed in Table I.

#### Table I Study demographics.

	#	%
Total women participating who underwent IVF	61	100
Age		
Median age of women at the birth of their first child	42 (40–46)	
Marital status		
Heterosexual marriages/partnerships	51	83
Same-sex marriages (female)	4	7
Single women	6	10
Children via IVF		
Median number of children per family	( -3)	
Median age of first child	3.5 (> - 0)	
Conception methods		
Families using IVF	46	75
Families using IVF with donor sperm	9	15
Families using IVF with donor eggs	6	10
Median months trying to conceive prior to IVF	6 (0-60)	
Average total cycles of IVF	2 (1-6)	
Ethnicity <sup>a</sup>		
Caucasian	51	84
African-American	2	3
Asian	4	7
Middle Eastern	2	3
Other	I	2
No ethnicity reported	I	2
Household Income		
\$50 000-\$74 999	I.	2
\$75 000-\$99 999	4	7
\$100 000-\$149 999	11	18
\$150 000-\$199 999	17	28
\$200 000-\$249 999	8	13
More than \$250 000	19	31
Not reported	I	2
Work		
Women with paid work at the time of interview	45	74
Women without paid work at the time of interview	16	26
Education		
Some college	3	5
College	22	36
Post graduate	36	59

<sup>a</sup>Rounding errors where totals do not equal 100%.

#### Pre-IVF awareness of age and infertility

The women in our cohort first attempted conception at an average age of 39 (range: 35-45) and 48% stated that they had some awareness that fertility declined after age 40 (Table II). Yet 30% of women expected their fertility to decline gradually until menopause at around

#### **Table II** Awareness of age and infertility (n = 61).

	<b># (%)</b>
Thought fertility declines after age 40	29 (48)
Expected decline to be gradual until menopause	18 (30)
Expected it to be easy to get pregnant at age 40	19 (31)

#### **Table III** Presumptions of fertility (n = 61).

	# (%)
Lifetime emphasis on pregnancy prevention	14 (23)
Expected that health, fitness or family history was indicator of personal fertility	16 (26)
Messaging from media/community mislead them about age and fertility	17 (28)

50 years and 31% reported that they expected to get pregnant without difficulty at age 40. Participants cited a number of explanations for their presumption of robust fertility, which are summarized in Table III. Of the participants, 23% recalled persistent and ongoing messaging about pregnancy prevention starting in adolescence, for example: 'I almost felt like I've been betrayed... because they tell you it's so easy to get pregnant ... it's like, all of our lives we're terrified we're going to get pregnant too soon and have a child and ruin our lives ... and, actually, it's not that easy'.

For 26% of women, there was a belief that their mothers', sisters' or their own previous fertility histories and/or healthy lifestyles indicated they would be fertile. One participant described: 'My mom had six pregnancies and four kids in five years ... It was never a concept that I wouldn't get pregnant' while another stated: 'I was an exercise fanatic ... I didn't understand that the eggs get old and whether or not you're in good shape really has nothing to do with it'. Of the participants, 28% cited incorrect information from friends or their doctors or misleading media reports of pregnancies in older celebrity women as reinforcing notions that older women can easily become pregnant. One 42-year-old women recounted thinking: 'Of course I'm not old. Everyone's having babies at 42 . . . all the superstars are having them'. A few women were skeptical of medical statistics and believed that their own situations were unique: 'It almost seems like the statistics they give are more negative than what you see amongst your friends...they give you the worst case scenarios'. Finally, one woman thought that information about age-related infertility was used to persuade women to have children earlier: 'We just thought it was scare tactics or something to make you have kids young and thought it would be just fine'.

#### Initiating fertility treatment-confronting 'age shock'

Participants estimated that they had tried to conceive for a median of 6 months (range: of 0-60 months) before seeking clinical assistance. Almost two-thirds of participants self-referred for fertility consultation

# **Table IV** Feelings about fertility information following IVF $(n = 61)^{a}$ .

	# (%)
Need better fertility education for younger women and men	17 (28)
Would have tried to conceive earlier with better information	14 (23)
Personal circumstances did not permit earlier childbearing regardless of fertility awareness	28 (46)

<sup>a</sup>Percentages do not total 100% as not all participants cited each theme, while others mentioned multiple themes.

while approximately one-third were referred by obstetrician/gynecologists or other doctors. When entering into the medical realm, very few participants had considered the possibility that they would need IVF and 44% reported being 'shocked' and 'alarmed' to discover that their understandings of the rapidity of age-related reproductive decline were inaccurate. This woman's description of her reaction was typical: 'I probably didn't know enough. I certainly didn't know about the great [fertility] cliff you fall off after 35'.

To compound their dismay, 52% of participants learned that even IVF offered them a limited chance for success. As this woman, who was 43 when she first attempted conception, explained: 'I think I had a very naïve notion [that] with the various reproduction technologies you could have a baby no matter what. That was what was really sobering'.

# Looking back-—would different information have accelerated conception efforts?

In retrospect, their belated recognition of the effect of age on fertility led 72% of the women to state that they felt 'lucky' or that they had 'beaten the odds' in successfully conceiving after IVF. There were 28% of women who advocated better fertility education earlier in life so that men and women could make more informed childbearing decisions (Table IV) and 23% who indicated that with more information about declining fertility they might have attempted conception at an earlier age. Typical statements included: 'I might have just tried to get more serious about finding the right guy sooner,' or 'You can put your career on hold, but you cannot put your children on hold and I never knew that'. Yet 46% of women acknowledged that even if they had possessed better information, their life circumstances would not have permitted them to begin childbearing earlier than they did. As this woman summarized: 'I should have learned more about it when I was younger but it just didn't seem like it was applicable, because I just wasn't ready to have a family yet'.

### Discussion

We found that women did not have a clear understanding of the age at which fertility begins to decline. Over half of participants were 'shocked' to discover that the chances of conception at their ages were much lower than they had anticipated. Their subsequent 'alarm' at discovering that women's fertility declines rapidly after age 35 (ASRM, 2008) led them to rapidly seek fertility treatment.

Cooke et al. (2010) meta-ethnography identified three degrees of informed decision-making about women's timing of childbearing attempts: (i) those who were uninformed, (ii) those who thought they were informed but had incomplete information and (iii) those who were informed but delayed childbearing nonetheless. Similar to Cooke's first group and our past research, a minority of participants reported being completely uninformed about age and fertility and felt let down or 'betrayed' by health care providers who had not shared such information (Friese et al., 2006; Cooke et al., 2010). But our sample most closely resembles Cooke's second group in that a majority of our participants incorrectly imagined a decline that begins near 40 or a gradual decline in fertility concluding at menopause. This underestimation of the impact of age on fertility is consistent with findings from other European and Canadian surveys of students who were being asked to consider fertility at an earlier stage of their lives (Lampic et al., 2006; Tyden et al., 2006; Bretherick

Even with some knowledge of the nature of an age-related fertility decline, why did these highly educated women not act to become pregnant earlier? A quarter of women in our study stressed a life-long focus on pregnancy prevention that may have contributed to overestimating their chances of conception even as they aged. In their UK study, Earle and Letherby (2007) argue that control over pregnancy prevention creates an 'illusion' of control over conception.

et al., 2010; Daniluk et al., 2012).

Over half of our sample reflected Cooke's third group who believed that the information did not apply to them personally because of misleading information from the media, their own healthy lifestyles or because of their family's history of multiple or late conceptions (Ryan et al., 2005; Bunting and Boivin, 2008). This deflection of information about age and fertility may also be seen as reflecting an increasing cultural trend toward the disassociation of biology and life stages through medical interventions (Hogle, 2003) which can 'challenge and subvert the temporal expectations of the reproductive body' (Earle and Letherby, 2007). After achieving success with IVF, almost three-quarters of women described feeling lucky, as if they had 'won the lottery' or 'beat the odds'. Past studies have similarly found that popular discourses attributed IVF failure or success to external factors such as luck or chance (Callan and Hennessey, 1988; Beaurepaire et al., 1994; De Lacey, 2002; van Balen, 2002; Redshaw et al., 2007). Gambling metaphors externalize IVF success or failure and highlight themes of loss of personal control for men and women undergoing fertility treatment (De Lacey, 2002; Greil, 2002; Redshaw et al., 2007). That themes of chance were frequently referenced in our cohort may have been in response to clinician messaging about 'low odds'. They may also reflect an effort to deflect personal blame for infertility potentially implicit in delayed childbearing (Friese et al., 2006) and instead situate themselves within an external discourse of luck and success (Earle and Letherby, 2007).

Another approach to the question of why these highly educated women possessed incomplete information about age and fertility is to note that despite the significant consequences at both individual and societal levels, the scientific understanding of age-related infertility has been relatively slow to evolve and even slower to disseminate. The 1982 report from the Federation CECOS in France was the first large-scale study to call attention to a detectable decline in artificial insemination pregnancy rates as women aged (Schwartz and Mayaux, 1982). Yet it wasn't until the late 2000s that the ASRM issued guidelines recommending that women who are attempting conception should receive expedited evaluation and treatment after they specifically reached the age of 35 (ASRM, 2008).

Another factor could be the unwelcome social implications of this information. A modest public education campaign undertaken by the American Society for Reproductive Medicine between 2000 and 2002 addressing the fertility risks of aging received criticism that age-related messaging imposed limits on women's reproductive choices, put pressure on women to bear children when they were not ready, undermined women's efforts to become educated, have careers and still raise families (Kalb, 2001; Lerner, 2001; Soules, 2003) and was 'inextricably entwined... with the ongoing struggles over birth control, abortion and women's position in the workplace' (Lerner, 2001). Some of these public discussions may have informed how our cohort understood and used the information they possessed about age and fertility. Yet in the intervening years, the demographic trend of delayed childbearing has continued (Chandra et al., 2005; Matthews and Hamilton, 2009), as has the escalating demand for ART in women over 35 (SART, 2009). Recent demographic projections suggest that a delay in the age at the start of attempted pregnancy will have a strong influence on the proportion of couples who remain childless five years later, and even widespread use of IVF will make up for only a small part of that fertility reduction (Leridon and Slama, 2008). These projections make a case for renewed attempts to educate women and men about the known parameters of fertility at all life stages (Tyden et al., 2006; Balasch and Gratacós, 2011).

In fact, we found that some women advocated improved education about women's fertility earlier in life in order to correct false peer, popular and media-generated information and to enable women to make more informed plans for childbearing. These findings echo those of other studies indicating that women have some general understanding of aging and fertility, but lack accurate or specific knowledge that could enable informed decision-making regarding their timing of childbearing (Slosar, 2003; Benzies et al., 2006; Friese et al., 2006; Tough et al., 2006, 2007; Carolan and Nelson, 2007). Some supported the idea of regular fertility testing for women, a finding supported by a recent survey on women's attitudes toward ovarian reserve testing (Bavan et al., 2011). Although it is debatable whether population-based testing of women's fertility is feasible or desirable, as the sensitivity and specificity of testing age-related subfecundity improves, there may be a case for testing younger women, even those not immediately attempting conception.

A more challenging observation is that while a number of women indicated that better information might have allowed them to make different choices facilitating earlier childbearing, they also endorsed the concept that most people's lives are situated within complex social and cultural circumstances that are not entirely under their control (Wu and MacNeill, 2002; Kemkes-Grottenthaler, 2003; Hammarberg and Clarke, 2005; Benzies *et al.*, 2006; Lampic *et al.*, 2006; Virtala *et al.*, 2006; Cooke *et al.*, 2010; Fry and Cohn, 2010; Furstenberg, 2010; Beck-Gernsheim, 2011; Slaughter, 2012). Tellingly, almost half of participants who had some knowledge about age and fertility did not act on it because they were not 'ready' for childbearing, including those who had life partners earlier (Mac Dougall *et al.*, 2012). Thus, more fertility education may not reduce age-related infertility as women delaying childbearing may be informed but not ready for

parenting because of competing demands of education, work and their relationship (Lampic *et al.*, 2006; Ryan *et al.*, 2005; Mac Dougall *et al.*, 2012).

We acknowledge that this study has several significant limitations. The overall study was designed primarily to explore the experiences of delayed parenting following IVF treatment and questions addressed both past and present events. Both the self-selected nature of recruitment and our retrospective design can result in biases due to memory limitations or participant assimilation and/or the contrast of past events with current moods (Schwarz, 2007). Within the context of the larger study, questions addressing fertility awareness before and after IVF treatment were necessarily retrospective. Self-selection and self-reporting is commonly used in qualitative health care research but has been criticized for introducing bias based both on participants' individualized comprehension of questions and on their desires to respond appropriately to researchers' (Schwarz, 1999). Recall bias may have led participants to over- or underestimate their previous fertility knowledge as respondents may resort to using inference strategies in which memories may be more aligned with current events than past events analysis (Schwarz, 2007). However, an exception to this is recall of peak 'highly memorable' episodes, such as the 'shock' that many experienced upon learning about the impact of age on fertility, which clearly stood out during data collection and analysis (Schwarz, 2007). Other studies designed specifically to explore fertility awareness may benefit from a prospective and/or randomized design (Daniluk et al., 2012, Bunting and Boivin, 2008, Maheshwari et al., 2008, Tough et al., 2006, 2007); however, we felt that lack of fertility awareness was a theme this cohort found to be highly meaningful. While the cohort did not reflect broad homogeneity in that participants were much more likely to be highly educated, Caucasian and better able to pay for treatment than national population norms, their demographic reflects the affluence of the San Francisco Bay area and is not dissimilar to those who utilize IVF in the United States in states without mandated insurance for IVF (Bitler and Schmidt, 2006; Jain, 2006; Hammoud et al., 2009). Yet the very fact that participants were highly educated and financially well-above average made their relative lack of knowledge and awareness concerning age-related infertility even more striking. It may be that their education and high socio-economic status may have been related to a greater focus on contraception than on fertility or contributed to choosing career paths that competed with messages to have children at a younger age. Finally, because this paper is based on data derived from a study specifically addressing the experience of women who became first-time parents after age 40 using IVF, attitudes of older women who were unsuccessful after attempting IVF in their late 30s or early 40s are not represented. Reflecting our experience with a different cohort of women who conceived after oocyte donation, it is possible (if not likely) that the recollections of women who did not conceive after IVF would have been more strongly influenced by feelings of regret or efforts to deflect blame for their inability to conceive (Friese et al., 2006).

### Conclusions

Women who were first-time parents over the age of 40 did not accurately perceive the relationship between age and fertility prior to conceiving with IVF. In response to their experiences with age-related infertility, they emphasized that they had 'beaten the odds' or been 'lucky' to conceive with IVF and some advocated better fertility education and testing earlier in life so that men and women could make more informed childbearing plans. Yet even with more information, almost half acknowledged that their personal-life circumstances would not have encouraged them to begin childbearing earlier than they did. As a result, we conclude that while the failure to appreciate the true biological relationship between aging and fertility may reflect inaccessibility or misinterpretation of information, it is not sufficient to explain the decades-long socio-demographic phenomenon of delayed childbearing.

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## **Authors' roles**

R.D.N., K.M.D. and Y.B. designed the study. K.M.D. and R.D.N. performed the analysis and drafted the paper. All the authors gave final approval for the version to be published.

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# **Conflict of interest**

None declared.

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