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Fertility knowledge and beliefs about fertility treatment: findings from the International Fertility Decision-making Study

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STUDY QUESTION: How good is fertility knowledge and what are treatment beliefs in an international sample of men and women currently trying to conceive?

SUMMARY ANSWER: The study population had a modest level of fertility knowledge and held positive and negative views of treatment. **WHAT IS KNOWN ALREADY:** Few studies have examined general fertility treatment attitudes but studies of specific interventions show that attitudes are related to characteristics of the patient, doctor and context. Further, research shows that fertility knowledge is poor. However, the majority of these studies have examined the prevalence of infertility, the optimal fertile period and/or age-related infertility in women, in university students and/or people from high-resource countries making it difficult to generalize findings.

STUDY DESIGN, SIZE, DURATION: A cross-sectional sample completed the International Fertility Decision-making Study (IFDMS) over a 9-month period, online or via social research panels and in fertility clinics.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Participants were 10 045 people (8355 women, 1690 men) who were on average 31.8 years old, had been trying to conceive for 2.8 years with 53.9% university educated. From a total of 79 countries, sample size was >100 in 18 countries. All 79 countries were assigned to either a very high Human Development Index (VH HDI) or a not very high HDI (NVH HDI). The IFDMS was a 45-min, 64-item English survey translated into 12 languages. The inclusion criteria were the age between 18 and 50 years and currently trying to conceive for at least 6 months. Fertility knowledge was assessed using a 13-item correct/incorrect scale concerned with risk factors, misconceptions and basic fertility facts (range: 0–100% correct). Treatment beliefs were assessed with positive and negative statements about fertility treatment rated on a five-point agree/disagree response scale.

MAIN RESULTS AND THE ROLE OF CHANCE: Average correct score for Fertility Knowledge was 56.9%, with greater knowledge significantly related to female gender, university education, paid employment, VH HDI and prior medical consultation for infertility (all P < 0.001). The mean agreement scores for treatment beliefs showed that agreement for positive items (safety, efficacy) was correlated with agreement for negative items (short/long-term physical/emotional effects) (P > 0.001). People who had given birth/fathered a child, been trying to conceive for less than 12 months, who had never consulted for a fertility problem and who lived in a country with an NVH HDI agreed less with negative beliefs. HDI, duration of trying to conceive and help-seeking were also correlates of higher positive beliefs, alongside younger age, living in an urban area and having stepchildren. Greater fertility knowledge was associated with stronger agreement on negative treatment beliefs items (P < 0.001) but was unrelated to positive treatment beliefs items.

LIMITATIONS, REASONS FOR CAUTION: There was volunteer bias insofar as more women, people of higher education and people with fertility problems (i.e. met criteria for infertility, had consulted a medical doctor, had conceived with fertility treatment) participated and this was true in VH and NVH HDI countries. The bias may mean that people in this sample had better fertility knowledge and less favourable treatment beliefs than is the case in the general population.

WIDER IMPLICATIONS OF THE FINDINGS: Educational interventions should be directed at improving knowledge of fertility health. Future prospective research should be aimed at investigating how fertility knowledge and treatment beliefs affect childbearing and help-seeking decision-making.

STUDY FUNDING/COMPETING INTEREST(S): Merck-Serono S. A. Geneva-Switzerland (an affiliate of Merck KGaA Darmstadt, Germany) and the Economic and Social Research Council (ESRC, UK) funded this project (RES-355-25-0038, 'Fertility Pathways Network'). L.B. is funded by a postdoctoral fellowship from the Medical Research Council (MRC) and the ESRC (PTA-037-27-0192). I.T. is an employee of Merck-Serono S. A. Geneva-Switzerland (an affiliate of Merck KGaA Darmstadt, Germany).

Key words: fertility / infertility / knowledge / treatment / awareness

Introduction

Despite a near universal desire for parenthood, people do not seem to behave optimally when it comes to their fertility. Research has revealed an increase in exposure to fertility-compromising risks [e.g. obesity, sexually transmitted infections (STI)], an increase in age at first birth (Schmidt et al., 2012), delay in infertile people seeking timely medical attention (Bunting and Boivin, 2007) and high discontinuation from fertility treatment (Brandes et al., 2009; Gameiro et al., 2012). Fertility knowledge and treatment beliefs could help explain these trends. The aim of the International Fertility Decision-Making Study (IFDMS) was to better understand decision-making with respect to fertility in order to ultimately assist people in optimizing their fertility health. The first goal in this programme, reported in the present article, was to ascertain fertility knowledge and treatment beliefs in an international sample of men and women currently trying to conceive.

Knowledge about fertility

Fertility knowledge in the general population is poor. The evidence indicates that people are unaware of the biological aspects of conception; they often overestimate the chances of pregnancy at the time of ovulation (Lampic et al., 2006), have low awareness of when women are most fertile (Byamugisha et al., 2006) and lack an understanding of the steep decline in female fertility after the age of 34 years (Lampic et al., 2006; Bretherick et al., 2010). Knowledge about the specific risk factors for lower fertility is limited (e.g. STI, smoking, alcohol consumption: Mosher and Aral, 1991; Roth and Taylor, 2001; Bunting and Boivin, 2008; Quach and Librach, 2008) and erroneous when it comes to factors that have no impact on fertility potential (e.g. being healthy is equated with being fertile, Blenner, 1990; Bunting and Boivin, 2008). Finally, while people are familiar with the term infertility (Quach and Librach, 2008) they lack a general understanding of what infertility is or its prevalence within the general population (i.e. people overestimate fertility, Hashiloni-Dolev et al., 2011) making it difficult for them to see infertility as a problem they could potentially have (Blake et al., 1997; Adashi et al., 2000). However, there are some limitations to this evidence base. Past research sampled mainly women; whilst past gender comparisons suggest fertility knowledge is poor regardless of sex (Lampic et al., 2006; Rovei et al., 2010), a few studies indicate that men may be particularly uninformed (Sydsjo et al., 2006; Quach and Librach, 2008). Many studies use university students (e.g. Lampic et al., 2006; Bunting and Boivin, 2007) making it difficult to generalize to the older childbearing population or people with less education. A recent survey addressed some of these issues by sampling a nationally representative sample of female Canadians (Daniluk et al., 2012). The results suggest that Canadian women were only moderately knowledgeable about fertility, although it should be noted that $\sim 50\%$ of items concerned aspects of fertility treatment that one would not expect the average Canadian to know about (e.g. cost of fertility treatment, eligibility criteria for clinics). Finally, only one survey (World Fertility Awareness Month, WFAM, 2006) has taken a global perspective on fertility knowledge but its conclusions could be undermined by the narrow focus of its survey. The survey contained many items still under investigation (e.g. effect of contraception on fertility) or that concern factors that vary between countries (e.g. prevalence of infertility, Boivin et al., 2007). As a result, knowledge differences between countries in the WFAM study may reflect different realities with respect to prevalence, common causes and other aspects of fertility.

Beliefs about treatment

Sub-optimal fertility behaviour may also be influenced by attitudes towards fertility medical consultation and treatments, especially if it prevents people from seeking the desired help. Negative beliefs about the safety, accessibility and cost of fertility treatment have been reported (Klonoff-Cohen and Natarajan, 2004; Benyamini et al., 2005) and shown to be associated with lower likelihood of seeking help (Bunting and Boivin, 2007). In a Dutch cohort study of 1391 couples with suspected fertility problems, ~25% discontinued medical consultations because of negative attitudes to treatment (Brandes et al., 2009). Normative, moral or cultural beliefs also affect help-seeking behaviours (e.g. Sundby et al. 1998; Unisa, 1999; Ali et al., 2001; Dyer, 2008). Conversely, overly optimistic attitudes about treatment success rates could affect the start of childbearing efforts. In a Swedish study of young people, most believed that assisted reproduction techniques (ARTs) could reverse the effect of delayed childbearing (Skoog Svanberg et al., 2006; Maheshwari et al., 2008), which is not the case (Leridon, 2004). Studies on specific interventions, for example, expectant management (van den Boogaard et al., 2011) or fertility preservation after cancer (Tschudin et al., 2010), show that attitudes are often dependent on the characteristics of the patient, doctor and/or context.

Correlates of knowledge and beliefs

It would be expected that women would know more about fertility than men because they tend to be first to consult their physician about a fertility problem (Berg and Wilson, 1991) and have more direct fertility experiences via their menstrual cycle and other events

(e.g. pap smears, giving birth). Having experience of help-seeking itself should impact on fertility knowledge and beliefs. For example, preparatory clinic information provided prior to fertility clinic appointments has been shown to increase knowledge (Takefman et al., 1990) and increase attendance at clinic appointments (Pook and Krause, 2005). Other individual factors (e.g. education, socioeconomic status) are likely to correlate with knowledge and beliefs, as shown in other areas of health (Hawkins et al., 2007). Country of origin also seems to be an important contextual factor. For example, American samples tend to attribute fertility problems to biomedical and chance factors (Tennen et al., 1991), whereas in Nigeria (Ola et al., 2008) and Pakistan (Ali et al., 2011) attribution to supernatural causes is still common.

The present study

In light of the current knowledge, the primary aims of the present study were to examine fertility knowledge and treatment attitudes in men and women actively trying to conceive and to ascertain whether these varied across gender, country and selected individual and contextual factors. To achieve our research goals, we developed an international survey that was translated into 12 languages. In line with the research reviewed above, it was hypothesized that better fertility knowledge and more favourable beliefs about treatment would be observed in women and be associated with higher education, parity, previous engagement in medical consultation and higher country development status. It was also hypothesized that more favourable treatment beliefs would be associated with seeking medical help (i.e. consultation for fertility problems).

Materials and Methods

Participants

The final sample consisted of 10 045 people currently trying to conceive (8355 women, 1690 men) from 79 countries (18 countries >100 participants per country). On average participants were 31.8 years old (SD = 5.9), married or living with their partner for 5.9 years (SD = 4.2) and trying to conceive for 2.8 years (SD = 2.9).

The inclusion criteria required participants to be between 18 and 50 years of age, currently married or living with their partner (sexual orientation was not requested), currently trying to conceive for at least 6 months (while participants were asked to only complete the survey if trying for at least 6 months, 4.1% of participants who completed the survey stated they had tried for <6 months. We decided to include these data in analyses. Similarly, in Facebook recruitment adverts, it was necessary to use the Facebook criterion of 18-44 because their next age increment (e.g. 45-55) included people >50 years) and not pregnant. The only exclusion criteria applied to recruitment in fertility clinics; patients using specialist fertility medical services were excluded, for example treatment for human immunodeficiency virus (HIV) sero-positive or HIV discordant or hepatitis C, PGD. The lower age limit was applied to avoid the need to obtain parental consent, whereas the upper age limit was applied because it is the upper end of natural fertility (ESHRE Capri Workshop Group, 2005). The criterion for partnership was applied to avoid heterogeneity in sample demographics because <4% of people intentionally choose to start a family outside of a partnership (Gonzalez and Jurado-Guerrero, 2006). The 'duration of trying' criterion was applied to balance the effects of fertility awareness on the factors investigated. On the one hand, people need to recognize a fertility problem might exist

before they begin to contemplate decision-making issues (Prochaska et al., 1992) and duration of failure to conceive is the most important sign of potential fertility problems. On the other hand, a fertility problem is likely to change fertility knowledge and attitudes and with longer durations of trying, attitudes could become mainly a consequence of the lack of fertility or of associated help-seeking (Bunting and Boivin, 2007). A 'duration of trying' entry threshold that was mid-way between the start of trying and start of referral to specialist care (usually 12 months, National Institute of Clinical Excellence, NICE, 2004) enabled us to capture the 'worrying-well' group and thereby early decision-making and potential precursors to help-seeking. The 'specialist treatment' exclusion was applied because in these patients the need for treatment arises from the medical condition (e.g. genetic condition) and not a fertility problem, per se.

Questionnaire design

The IFDMS centred around two decision points: the decision to have a child and the decision of what to do if natural attempts were unsuccessful. Psychological (e.g. Theory of Planned Behaviour, Ajzen, 1991; Health Belief Model, Rosenstock, 1990) and fertility (e.g. Preference theory, Hakim, 2000) theories and a systematic review of published literature regarding reproductive decision-making informed the selection of items for the IFDMS project. Survey wording was adapted to be appropriate to men and women and to people who had/had not sought fertility treatment. The final survey consisted of 64 items covering five broad domains of decision-making. Only those questions relevant to analyses presented in this paper are described (for full survey see www.startingfamilies.org).

Fertility knowledge

Fertility knowledge was assessed using a 13-item questionnaire that investigated knowledge in three areas (see Appendix). The items were selected from other studies to examine knowledge categories known to be associated with fertility decision-making: (i) indicators for reduced fertility (e.g. smoking, weight, history of STIs and mumps after puberty); (ii) misconceptions about fertility (e.g. woman fertile even without periods) and (iii) basic facts about infertility (e.g. recommended time limit for referral to a specialist, base rate of infertility) (Blenner, 1990; Adashi et al., 2000; NICE, 2004; Bunting and Boivin, 2007; Bunting and Boivin, 2010). The response scale was true, false or don't know. A correct answer was assigned one point and an incorrect or don't know answer zero points. Points were summed, divided by the total number of questions and multiplied by 100 to produce a percentage correct fertility knowledge score with a range of zero to 100%. An exploratory factor analysis showed that all items loaded > 0.30 on one general factor that accounted for 30% of between-item variance and descriptive statistics (on the present sample) showed the composite scale to be normally distributed (data not shown). Internal reliability (standardized Cronbach alpha coefficient) was moderate ($\alpha=0.79$) and satisfactory for most countries (except for Italy 0.59 and Turkey 0.41).

Treatment beliefs

Participants were presented with six (two positive and four negative) beliefs about treatment culled from treatment-seeking research (White et al., 2006; Bunting and Boivin, 2007; Boivin et al., 2012): fertility treatment is very safe, most people who start fertility treatment eventually get pregnant, fertility treatment is a scary experience, fertility treatment may have short-term physical effects (e.g. headaches, nausea), long-term term physical effects (e.g. cancer) and fertility treatment can cause emotional problems. Participants indicated whether they agreed or disagreed with each statement using a five-point response scale (I = strongly disagree to 5 = strongly agree). Responses were summed to create a positive

(two items) and negative treatment belief score (four items) with higher scores indicating more agreement with positive or negative treatment beliefs (range I–5). An exploratory factor analysis showed that negative items loaded $>\!0.60$ on their respective negative or positive factor (accounting for 53% of between-item variance) and descriptive statistics (on the present sample) showed the composite negative scale to be normally distributed (data not shown). The standardized Cronbach alpha coefficient for the total sample was $\alpha=0.62$ for the negative treatment belief score (country range $\alpha=0.52-0.76$, except New Zealand $\alpha=0.40$). The correlation between the two items of the positive scale was r=0.31.

Socio-demographic variables

Participants stated their country of residence, age in years, the number of years they had been living together/married with their partner, whether they resided in an urban area (yes/no) and whether they and their partner had paid employment (yes/no). Education was categorized according to whether or not the participant had a university education (yes/no). Country of residence was categorized according to the number of participants. There were 18 countries reaching >100 respondents (as per our target, see the section Procedure) with remaining countries labelled 'other'. All countries of residence (even those with fewer than 100 respondents) were grouped according to the 2010 Human Development Index (HDI) rankings compiled by the United Nations Development Programme (UNDP, http://hdr.undp.org/en/statistics/, last accessed 26 October 2011). The index combines life expectancy, educational attainment and income as a reference for social and economic development, and ranks countries into four categories of development (very high, high, medium and low). Countries were categorized according to whether they met the Very High Human Development Index (VHHDI) or not a VHHDI (NVHHDI). There were 32 countries categorized as VH HDI (13 countries > 100 respondents per country) and 47 countries categorized as NVH HDI (five countries > 100 respondents per country).

Fertility status

Participants indicated whether they had given birth/fathered a child (number, with or without treatment), whether they had adopted and/ or had any stepchildren (yes/no), how long they had been trying to conceive (in years) and whether they had sought a medical consultation and/ or treatment for their fertility (yes/no). Medical consultation referred to seeking advice from a medical doctor, undergoing fertility diagnostic testing, ovulation induction, insemination, surgery and/or treatment with ART. Participants were categorized according to whether or not they met the clinical criteria for infertility, as defined by the International Committee for Monitoring Assisted Reproductive Technology and the World Health Organization Revised Glossary on ART Terminology (Zegers-Hochschild et al., 2009), namely, whether the participant had been trying to conceive for 12 or more months (infertility status, yes/no).

Translations

The survey was produced in English, tested with potential users and then translated to 12 languages [Danish, French, German, Italian, Spanish, Portuguese (European & Brazilian), Turkish, Japanese (Nihongo), Hindi, Russian, Chinese (Mandarin)]. The Cardiff University Centre for Lifelong Learning Translation service carried out the first translation from English to the target language. Local fertility experts examined the first translation against the English version and proposed revisions to ensure the two were consistent, and appropriate to fertility usage and local custom. The version agreed by fertility expert and translator was used in the survey. The survey was uploaded using SurveyTracker software (Training Technologies, 2007)

or software used by the market research companies involved in the project: Ipsos-Health for Turkish, Japanese, Russian and Hindi and IMS-Health for China (recruitment details below).

Procedure

The data collection period was from July 2009 to April 2010. We used multiple data collection methods (social research panel, fertility clinic or online) according to what was feasible in each target country. The 18 target countries were selected in collaboration with the pharmaceutical company and in consideration of the wider aims of the research council grant (ESRC) that funded the project and included: Australia, Canada, Denmark, France, Germany, Italy, Japan, New Zealand, Portugal, Spain, UK, USA, Brazil, China, India, Mexico, Russia and Turkey.

Market research companies performed data collection in four of the target countries [Japan, Russia and India (Ipsos-Health] and China [IMS-Health)] using social research panels (SRPs) because online recruitment was limited in those countries. Participants were also recruited from 28 fertility clinics in India and in China (number of clinics in China not recorded). IFDMS project workers distributed paper versions of the survey to clinics where patients attending appointments were invited to participate by medical personnel (opportunity sampling). Participants in the remaining 14 countries were recruited online via paid advertising on search engines (Google) and social media websites (Facebook), posting a study hyperlink on topic relevant websites (e.g. Babycentre, patient advocacy sites, fertility clinics), or via direct or indirect traffic (e.g. magazine articles, word of mouth, etc.) to the IFDMS website (www.startingfamilies .com). For all online methods, a banner about the IFDMS (e.g. 'Trying to conceive? Contribute to fertility survey from Cardiff University') and a study hyperlink were placed at an appropriate position on the website. The online links received traffic from other countries and we also included these data.

The questionnaire took $\sim 0-45$ min to complete. The online survey was identical to the one used on SRPs and in fertility clinics. The Ethics Committee of the School of Psychology, Cardiff University carried out the ethical review and approved the IFDMS study procedure (for online and SRP data collection). Ethical review and approval was additionally gained from each clinic as per country requirements. Participants were presented with an online consent form, including information on how to exit the survey if at any point they did not want to continue. No data were collected from participants who dropped out during completion. At the end of the survey participants had to click a submit button to submit data to the study.

Data analysis

A power calculation was computed to identify a minimum country sample size for intended analyses. Power calculations for analysis of variance (with effect size $f=0.25,\ \alpha=0.05,\ {\rm power}=0.85)$ and for regression (with effect size $f^2=0.15,\ \alpha=0.05,\ {\rm power}=0.85)$ indicated a minimum sample size per country of 97 (G*Power, Faul et al., 2007). A total of 10 615 responses were received and downloaded, of which 154 (1.45%) were identified and removed as duplicate cases because the data were identical for all 64 items. Preliminary data screening produced 278 (2.62%) participants who were excluded from analyses owing to incomplete data (>50% of data missing) and 138 (1.30%) who were excluded because of invalid data (e.g. participant started trying to conceive at the age of 5 years). The final sample size after exclusions was 10 045.

Chi-square, t-tests and analysis of variance were used to compare sociodemographic (age, education, employment, residential area, country development status), fertility (years married, parity, adopted/stepchildren) and infertility (years trying to conceive, infertility status, medical help-seeking)

characteristics of the sample by gender, recruitment source and HDI index. Parametric tests were also used to compare fertility knowledge and treatment beliefs according to sample characteristics, source and HDI. Countries with at least 100 participants (i.e. 18 countries) were listed by name in country data presentations, or, if fewer participants, were grouped as 'other'. We performed country analyses to ascertain whether the country variable explained the variation in fertility knowledge and treatment favourability. However, we did not follow-up significant effects with pairwise post hoc tests owing to the number of comparisons (i.e. 153 comparisons) and the alpha inflation this would entail for 18 countries. We did, however, compare knowledge and beliefs according to country HDI. As the sample was large, a probability value of P < 0.01 was considered statistically significant and Rosenthal-r', an effect size measure (Rosnow and Rosenthal, 2003), was reported to aid in interpretation (r = 10, 0.30, 0.50 considered small, medium, large effects, respectively, Cohen, 1992). To reduce the risk of alpha inflation, Bonferroni correction was applied to the family of comparisons (alpha/number of comparisons in family, see Results). Analyses were performed using the software Statistical Package for the Social Sciences.

Results

Socio-demographic and fertility characteristics of the sample

Table I shows socio-demographic and fertility characteristics according to the total sample, gender and HDI. Data according to each country are presented in Supplementary data, Table S1.

Total sample

The majority of respondents were female (83.2%), in their early 30s, had received a university education, and they and their partner had paid employment. The majority lived in urban areas 75.8% (n=7585). Participants had been living with their partners ~ 6 years and 26.3% had previously given birth/fathered a child (19.4% conceiving with fertility treatment), 1.2% had adopted at least one child and 11.1% reported having at least one stepchild. Participants had been trying to conceive for almost 3 years, 75.7% already met the definition for infertility and 71.5% had already sought a medical consultation for their fertility.

Gender comparisons

Women were significantly younger than men (t(10019) = 10.2, P <0.001, r' = 0.10), significantly less likely to have received a university education ($\chi^{2}(1) = 27.4$, P < 0.001, r' = 0.05) or have paid work $(\chi^2(1) = 79.2, P < 0.001, r' = 0.09)$ but more likely to have a partner that had paid employment ($\chi^2(1) = 816.3$, P < 0.001, r' =0.30). Men and women were equally likely to live in urban areas $(\chi^2(1) = 3.3, P < 0.06)$. There was no gender difference in years together/married (t(9990) = 0.132, P < 0.895) or the likelihood of having a biologically related child (or children) ($\chi^2(1) = 0.64$, P <0.42) or to have adopted ($\chi^2(1) = 4.4$, P < 0.05). Women were significantly more likely than men to have a stepchild ($\chi^2(1) = 41.1$, P <0.001, r' = 0.06). The duration of trying to conceive (t(9981) = 1.43, P < 0.15) and percentage trying for 12 months or more was similar $(\chi^2(1) = 0.016, P < 0.90)$ by gender but women were significantly more likely to have sought a medical consultation for their fertility $(\chi^2(1) = 157.9, P < 0.001, r' = 0.13)$ than men. Effect size was

small (<0.10) for most gender comparisons except difference in partner's employment status, which was moderate (0.30).

HDI comparison

Participants from VH HDI countries were significantly older (t(9943) = 6.0, P < 0.001, r' = 0.06), were less likely to have a university education ($\chi^2(1) = 289.3$, P < 0.001, r' = 0.17) but equally likely to live in urban areas ($\chi^2(1) = 5.2$, P < 0.05) compared with the NVH HDI country participants. Participants from VH HDI countries were more likely to be in paid work ($\chi^2(1) = 203.0$, P < 0.001, r' = 0.12) and have partners in paid work ($\chi^2(1) = 134.9$, P < 0.001, r' =0.14) than participants from NVH HDI countries. Participants from VH HDI countries had been living with their partner for longer (t(9922) = 6.13, P < 0.001, r' = 0.06) and were more likely to have given birth/fathered a child ($\chi^2(1) = 27.8$, P < 0.001, r' = 0.05). However, participants from VH HDI countries were less likely to have adopted ($\chi^2(1) = 13.9$, P < 0.001, r' = 0.04) or have stepchildren ($\chi^2(1) = 12.1$, P < 0.001, r' = 0.04) compared with participants from NVH HDI countries. Participants from VH HDI countries had been trying to conceive for less time (t(9905) = 6.71, P < 0.001,r' = 0.07) and more likely to have sought a medical consultation for their fertility problem ($\chi^2(1) = 18.0$, P < 0.001, r' = 0.04) but they were equally likely to be infertile ($\chi^2(1) = 0.002$, P < 0.963) compared with participants from NVH HDI countries. Effect size was generally small (<0.10) except for education and employment status (self, partner), which were small to moderate. The socio-demographic and fertility profile for individual countries are also shown in Supplementary data, Table S1.

Fertility knowledge and treatment beliefs

Table II shows fertility knowledge and treatment beliefs according to sample characteristics with these data illustrated in Figs I and 2, according to the total sample, by gender, country HDI index and by country of residence.

Figure 1 shows the fertility knowledge percentage correct score for the total sample and according to gender, country HDI index and country of residence. The overall fertility knowledge score was 56.9% (SD = 24.7). Table II shows that the correlates of fertility knowledge were mainly related to socio-demographic factors. Higher fertility knowledge was observed in women, people of older age, university education, having paid work (self, partner), living in an urban area and residing in a VH HDI country. Fertility characteristics (birth, adoption, stepchildren) and infertility status were not related to fertility knowledge but people who had consulted a medical doctor were more knowledgeable. Effect size was between small and moderate for all differences except age, which showed a small effect size. Figure I also shows significant variation in fertility knowledge across countries (F(19, 9881) = 297.8, P < 0.001) with the lower bound being scores from participants in Turkey (17.1%) and the upper bound being scores for participants in New Zealand (79.0%).

Figure 2 shows the negative and positive treatment belief scores for the total sample and according to gender, country HDI and country of residence. The mean agreement scores for positive items (safety, efficacy) were similar (M=3.39, SD = 0.85) to agreement for negative items (short/long-term physical/emotional effects) (M=3.41, SD =

Table I Results of the International Fertility Decision Making Study presented according to total sample (n = 10045), gender (n = 8355 women and 1690 men) and HDI.

Variable	Total	Gender		Effect size	Human development index		r′ HDI
		Women	Men	r' gender	VH	NVH	
Demographic			• • • • • • • • • • • • • • • • • • • •			• • • • • • • • • • • • • • • • • • • •	
Age in years	31.8 (5.9)	31.6 (5.8)	33.2 (6.3)***	0.10	32.1 (5.9)	31.4 (5.9)***	0.06
Years together	5.9 (4.2)	5.9 (4.1)	5.9 (3.4)		6.1 (4.1)	5.6 (4.2)***	0.06
University education (%, n)	53.9 (5391)	52.7 (4387)	59.7 (1004)***	0.05	47.3 (2916)	64.8 (2449)***	0.17
Paid work (%, n)	76.9 (7637)	75.2 (6207)	85.3 (1430)***	0.09	80.8 (4935)	70.7 (2648)***	0.12
Partner paid work (%, n)	87.2 (8645)	91.5 (7545)	65.9 (1100)***	0.30	91.0 (5547)	81.1 (3034)***	0.14
Living in urban area (%, n)	75.8 (7585)	75.4 (6280)	77.5 (1305)		75.1 (4613)	77.0 (2914)	
Fertility							
Given birth/fathered child(%, n)	26.3 (2581)	26.1 (2128)	27.1 (453)		28.1 (1700)	23.3 (861)***	0.05
Adopted child(ren) (%, n)	1.2 (117)	1.1 (89)	1.7 (28)		0.9 (52)	1.7 (63)***	0.04
Stepchild(ren) (%, n)	11.1 (1096)	12.1 (986)	6.6 (110)***	0.06	10.3 (624)	12.6 (467)***	0.04
Infertility							
Number of years trying to conceive	2.8 (2.9)	2.8 (2.8)	2.9 (3.4)		2.6 (2.6)	3.0 (3.3)***	0.07
Trying to conceive $>$ 12 months (%, n)	75.7 (7562)	75.7 (6292)	75.9 (1270)		75.8 (4643)	75.8 (2866)	
Consulted medical doctor (%, n)	71.5 (7180)	74.8 (6186)	59.7 (994)***	0.13	73.9 (4524)	69.9 (2611)***	0.04

VHHDI, very high HDI (Australia, Canada, Denmark, France, Germany, Italy, Japan, New Zealand, Portugal, Spain, UK, USA, Other; NHV, Not Very High HDI (Brazil, China, India, Mexico, Russia, Turkey, Other). See Supplementary data, Table S1 for individual country data. Data are the mean (SD) unless stated otherwise. Owing to missing data *n* varies per variable, 9740–10 000. All participants had data for gender and 81 participants missing data on HDI. r' = Rosenthal effect size. r' = 0.10, 0.30, 0.50 considered small, medium, large effect size, respectively.

0.77) (t(9782) = 1.51, P > 0.01). Table II shows the correlates of the negative and positive treatment belief scores. More negative treatment beliefs were observed in women, people with a university education, paid work (self, partner) and those living in a country with a VH HDI. People who had not given birth/fathered a child, been trying to conceive for more than 12 months and who had consulted a doctor also had more negative treatment beliefs. There was significant country variation in treatment beliefs (F(19, 9778) = 57.01, P < 0.001), with participants from New Zealand having the highest negative treatment belief score (3.88) and participants from China the lowest (2.96). Effect sizes for negative treatment belief comparisons were less than small (<0.10) except for gender and HDI, which were small to moderate. Comparisons for positive treatment beliefs showed that more positive beliefs were associated with being younger, living in an urban area, residing in a country with a NVH HDI and trying to conceive for <12months. Having stepchildren was also related to holding positive treatment beliefs. Gender, education, paid employment (self, partner), birth, adoption and prior consultation with doctor were unrelated to positive treatment beliefs. There was significant country variation in positive treatment beliefs (F(19, 9862) = 50.81, P < 0.001), with participants from India having the most positive treatment belief score (3.74) and participants from Japan the lowest (2.81). Effect sizes for treatment belief scores were less than small (<0.10) except for trying to conceive which was small to moderate (<0.18). Greater fertility knowledge was associated with stronger agreement with negative beliefs items (r(9786) = 0.290, P < 0.001) but was unrelated to positive beliefs items (r(9886) = 0.011, P = 0.278).

Discussion

The IFDMS recruited 10 045 people from 79 countries, which makes it the largest international survey on fertility decision-making. Overall, people had a modest level of fertility knowledge and held positive and negative views of treatment. Knowledge and beliefs were determined by socio-demographic factors as well as fertility and infertility experiences. Educational interventions should be directed at improving knowledge of fertility health, especially in lower resource countries and in men, and at ensuring a balanced view of fertility treatment. Future prospective research should be aimed at investigating how fertility knowledge and treatment beliefs affect childbearing and help-seeking behaviour.

Fertility knowledge was modest with a 57% average correct score (17–79%). We consider this to be a modest score relative to the maximum score possible of 100% but better than what has been reported for other common diseases such as cancer (e.g. 33% correct, Wardle et al., 2001). The fertility knowledge questions were reliable ($\alpha > 0.79$) and referred to important content that could help people safeguard their fertility (e.g. risk factors associated with impaired fertility), avoid over- or underestimation of fertility (e.g. popular misconceptions, base rate for infertility) and/or help people seek timely medical advice (e.g. months required to meet criteria for infertility). As such, the relatively poor knowledge level in many countries could jeopardize fertility health. Indeed explanatory models for behaviour change put knowledge at the core of why people do not behave optimally when it comes to health issues.

^{***}P < 0.001 refers to level of Bonferroni-corrected significance for t-test between categories of gender or HDI category.

Table II Scores for fertility knowledge and treatment belief.

Variable	Fertility knowledge	Treatment beliefs			
		Negative	Positive		
Demographic					
Women	59.09*** [0.19]	3.47*** [0.18]	3.40		
Man	46.22	3.10	3.38		
Age <34 years	55.85***[0.06]	3.40	3.45*** [0.08]		
Age ≥34 years	58.70	3.42	3.31		
No university education	53.70*** [0.12]	3.37***[0.05]	3.39		
University education	59.70	3.45	3.40		
No paid work	49.45*** [0.17]	3.32*** [0.06]	3.41		
Paid work	59.26	3.44	3.39		
Partner no paid work	44.83***[0.19]	3.22*** [0.09]	3.41		
Paid work	58.77	3.44	3.39		
Not living in urban area	48.13***[0.20]	3.40	3.32*** [0.05]		
Living in urban area	59.73	3.41	3.42		
NVH HDI	44.93***[0.40]	3.18***[0.24]	3.55*** [0.05]		
VH HDI	64.29	3.55	3.29		
Fertility					
Not given birth/fathered a child	57.09	3.43***[0.04]	3.40		
Given birth/fathered a child	56.66	3.36	3.38		
No adopted child(ren)	56.99	3.42	3.39		
Adopted child(ren)	56.68	3.48	3.22		
No stepchild(ren)	57.01	3.41	3.38***[0.04]		
Stepchild(ren)	56.85	3.41	3.49		
Infertility					
Trying to conceive < 12 months	56.52	3.31*** [0.07]	3.46*** [0.18]		
Trying to conceive \geq 12 months	57.06	3.44	3.37		
Not consulted a medical doctor	49.21*** [0.19]	3.22*** [0.16]	3.38		
Consulted medical doctor	60.00	3.49	3.40		

All data are presented as the mean (effect size; r'). r' = Rosenthal effect size; r' = 0.10, 0.30, 0.50 considered small, medium, large effect size, respectively. Owing to missing data n varies per variable, 9740–10 000. Scale fertility knowledge 0–100%, treatment beliefs 1–5. SD varied between 22 and 25 for fertility knowledge; 0.7 and 0.8 for negative treatment beliefs and 0.8–0.9 for positive treatment beliefs.

***P < 0.001 refers to Bonferroni-adjusted level of significance for difference test between categories of same variable (e.g. men versus women, >34 versus <34 years, etc.).

The factors that explained variation in fertility knowledge were mainly socio-demographic (e.g. education, employment, country development index) and help-seeking variables, rather than fertility or parenting variables (e.g. parity, adoption, stepchildren). These findings suggest that fertility knowledge is primarily linked to education rather than personal fertility and/or parenting experiences. The negative association between education and health literacy has been observed in other health contexts (cancer, diabetes, HIV) (DeWalt et al., 2004). Therefore, to improve fertility health, concerted educational efforts will be needed in schools, health clinics and other opportune locations. Increasing knowledge of signs, symptoms and preventable causes of other common diseases (e.g. breast cancer) has been found to reduce risk and reduce delay in seeking help, and to improve health outcomes (Oliveria et al., 1999; Grunfeld et al., 2003). We would expect similar benefits

from increasing fertility knowledge. Fertility awareness tools could help to achieve these goals (see Bunting and Boivin, 2010 for Ferti-STAT tool).

Treatment beliefs were generally balanced with respondents scoring slightly above the mid-point for positive (safety and efficacy) and negative items (short- and long-term negative physical and mood effects), with remarkably little variation between countries. The modest reliability for the set of negative beliefs items implied that items were unlikely to be tapping a homogeneous belief construct. The strongest associations between study variables and treatment beliefs (negative, positive) suggest that treatment beliefs were related to both education and fertility experiences. First, people having had a birth/fathering experience held less negative treatment beliefs. This appears to be linked to the experience of having had a biologically related child rather than parenting itself because people with adopted and/or stepchildren did

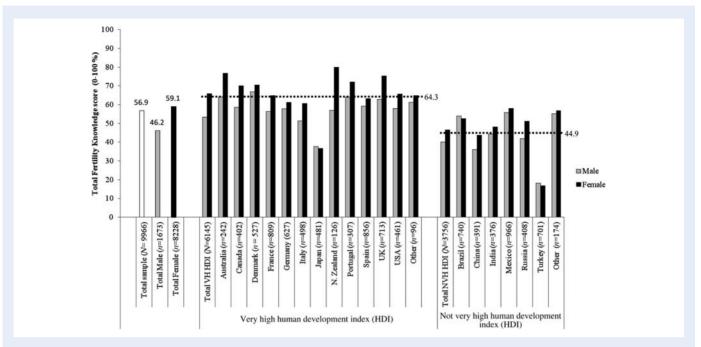


Figure 1. Average total fertility knowledge scores according to gender, country development status and country of residence. *Note*: other refers to countries with less than 100 participants. Dotted line represents the average total fertility knowledge score for the VH HDI and the NVH HDI countries.

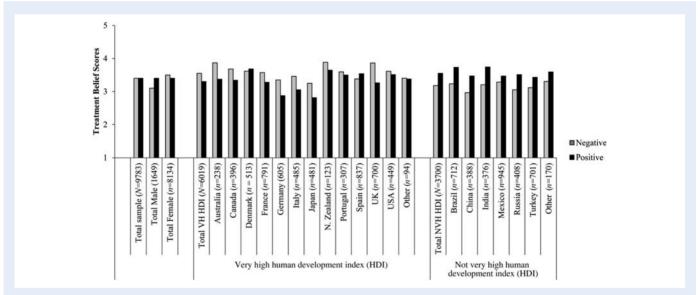


Figure 2. Average negative and positive treatment belief scores according to gender and country of residence. *Note*: other refers to countries with fewer than 100 participants.

not report less negative treatment beliefs. Secondly, people with relative educational disadvantage (less than university education, unemployed, NVH HDI) and/or relatively less infertility experience (shorter duration of trying to conceive, lack of medical experience) held less negative treatment beliefs: associations with positive treatment beliefs were in line with these findings. Taken together, this pattern of results suggests that treatment perceptions are initially

somewhat naïve but become more realistic with increased education and/or actual medical experience. The result that knowledge was associated with negative but not positive beliefs suggests that what changes with experience and knowledge is greater appreciation of the negative aspects of treatment (e.g. physical, emotional effects) in the context of generally stable positive beliefs about safety and efficacy. This realism has been associated with decision-making about

further treatment (Callan et al., 1988). The provision of balanced information about fertility treatment has been advocated since the early days of ART (Leiblum et al., 1987). However, it could be that a genuine appreciation of what treatment fully entails can only be realized when people have had their own experience of it. Therefore, healthcare professionals need to keep in mind that individuals consulting for the first time may have a lower capacity to fully integrate the negative aspects of treatment into their perspective.

Gender differences were consistent with expectation and in this respect provided validation for the survey methods. However, the pattern of gender results also reinforces that research on fertility and parenting issues continues to be a female-dominated domain. The majority of people responding to the survey were women (89%, 9:1, female:male ratio) despite our best efforts to recruit men. Fewer men may have been recruited because they were not searching on fertility-specific websites (e.g. infertility, pregnancy/parenting websites) where we posted the survey links. The gendered nature of interest in fertility may reflect social norms and/or lower male interest in childbearing. Additionally, Banks (2001) suggests that the male maxim of 'strength in silence' makes men reluctant to obtain information, whereas most women tend to actively do so in order to decide on the appropriate treatment before consulting a doctor (White et al., 2006). This lower male engagement may partly explain the lower fertility knowledge and lower likelihood of seeking medical help for fertility problems among men in the present sample, as well as holding less negative treatment beliefs compared with women. Future research needs to examine why men know less and how this may impact on their help-seeking and fertility health. Importantly, this goal can only be achieved if better methods of recruiting men are identified.

The results show similarity and difference among countries in their fertility knowledge and treatment beliefs. Pairwise country comparison tests were not computed because of the large number of comparisons this would have entailed (>150 comparisons). However, we have provided individual country data to support future research on fertility health awareness in specific countries. Furthermore, broad level comparisons according to country HDI were computed. Results from the present study validate the HDI index in that participants residing in countries with a VH HDI were more likely to be employed and to have partners with employment compared with countries with a NVH HDI. Unexpectedly, education was higher in the NVH HDI countries but this is likely to be an artefact of our methods (i.e. online surveys require access to a computer and the Internet). Importantly, our results show that the country HDI could also have implications for fertility and infertility. Fertility knowledge was greater in countries with a VH HDI. Further, people from the very high index countries were trying to conceive at an older age and later in their partnership, but showed less delay in seeking medical consultation (i.e. more had sought help after a shorter time of trying to conceive). The average difference in years trying to conceive between not and very high HDI medical consulters was 18 months. This pattern of results is likely to be related to healthcare contexts (e.g. access to fertility services) and complex demographic trends (e.g. delayed childbearing) clearly related to components of HDI. As such, HDI may be a worthy variable to consider in future fertility research and endeavours aimed at reducing disparity between low and high resource countries in access to infertility services.

We recruited participants online, via SRPs and in clinics, and it is important to consider results in the context of the strengths and weaknesses of these methods. Online recruitment was clearly successful with 8445 participants from >18 countries recruited over a 9-month period. Our experience shows that online recruitment is most effective when using paid advertising or posting on topic-relevant sites, because spontaneous traffic to the study website was very low (<5%, though 34% of people did not state where they obtained the IFDMS study link). Overall, multiple online methods work but they are liable to volunteer bias (education, personal relevance, source), especially in lower HDI countries. The main biases in recruitment were related to the population likely to be attracted to childbearing surveys, such as the IFDMS. The overall sample was mainly of people who already met the criteria for infertility and who had already sought medical advice/treatment for their fertility problems. Population surveys have shown that \sim 55% of people with fertility problems consult a medical doctor in low (including India and China) and highresource countries (Boivin et al., 2007). The results of the IFDMS confirm that seeking advice was similar in high- and low-resource countries (74 and 70%, respectively), although the proportion is higher than found by Boivin et al. (2007). Further, the IFDMS sample showed that the proportion accessing treatment was similar in low- and high-resource countries (49.3 versus 47.5% respectively), but again higher than in previous population surveys (Boivin et al., 2007). In addition, in the IFDMS nearly 20% of those who had given birth/fathered a child had conceived previously with fertility treatment, a much higher percentage than in the general population (2-3%, Nyboe Andersen et al., 2006). In other words, the methodology used in the IFDMS mainly attracted people for whom fertility issues were of personal relevance and this applies to countries from both development indices. This bias may partly be related to our inclusion criterion that participants were trying to conceive for a minimum of 6 months, as the majority of normally fertile couples (73%) will have conceived by that point (Evers et al., 2002). An additional bias is that the sample was likely to be drawn from higher socioeconomic groups, owing to the high percentage with a university education and paid employment (participant and their partner), which was much higher than the estimated 6.7% of the world who achieve a college/university degree (Barro and Lee, 2010). This is especially so in countries with a not VH HDI (i.e. >65% university education in China, India) because access to computers is still a privilege of the higher economic classes in these countries. As access to the Internet increases, reducing the digital divide across countries, such biases should reduce as has happened in the VH HDI countries. However, education bias is pervasive in any kind of research, including fertility research, even when recruitment is via conventional methods (Shelton et al., 2009).

The implication of the gender, personal relevance and education bias for our results is that fertility knowledge is likely to be overestimated and treatment beliefs less favourable (i.e. stronger negative and weaker positive beliefs) in the present sample than would be the case in a more representative sample of the general population. This conclusion is based on the findings that female gender, high education and personal experience of fertility/infertility issues was related to knowing more about fertility health issues and having greater appreciation of the negative aspects of treatment, as discussed earlier. Therefore, the main conclusions (i.e. need for education and balanced

view of treatment) could be more emphatically made when speaking of the general population. Despite the biases presented, the methodology (recruitment, survey questions) was validated in that many well-established findings were replicated: women were younger than men, were less educated, were less likely to work but more were likely to have working partners. Further, differences in fertility knowledge were as expected according to gender, country development index, etc. To achieve a broader representation of people trying to conceive one would need to carry out a survey using stratified sampling in the community (gender, age, duration of trying to conceive). Alternatively, exclusion criteria in online surveys could be set to achieve the same goal.

Aside from these biases other methodological issues warrant consideration in future research. The participants recruited from SRPs were much more likely to be parents (42 versus 16% in clinic and online samples, except for China, 5.3%, due to one child policy) and much less likely to have sought medical help (41.6 IPSOS versus 82% clinic/online), particularly in Japan and Russia (data not shown). This difference in fertility/infertility experience likely reflects the composition of research panels and their operation. SRPs comprise a finite population generated to reflect the industries they serve (e.g. consumer goods) and the people who purchase these goods (e.g. traditional households). In contrast, people recruited from clinics were, as one would expect, less fertile (i.e. less likely to be parents from a birth, adoption or stepchildren) and more infertile (e.g. longer duration of infertility and more likely to be infertile) (data not shown).

Strengths and limitations

Cross-sectional surveys have limitations that bear further upon the interpretation of our results. All variables were measured at the same time therefore we cannot disentangle cause from consequence; greater knowledge may cause people to have less favourable treatment beliefs but the reverse may equally be true. The strength of association among study variables is determined by reliability of the measurement tools and, in the case of treatment beliefs, this was modest. Association may therefore be underestimated for some of the items. To ascertain the impact of lower reliability, we carried out individual item analyses and found that results were mainly consistent across 12 study variables (i.e. age, gender, education, etc.) for the six treatment beliefs items. The few exceptions were that older women and urbanites perceived treatment to be more scary but less likely to cause emotional problems than did men or nonurbanites, and that some items showed weaker associations than others (i.e. safety and long-term effects of treatment). This more in-depth understanding of treatment beliefs should be addressed in future research. Fertility knowledge for Italy and Turkey and treatment beliefs for New Zealand may be better estimated with other methods owing to low reliability of the scales in these countries. The English survey was translated by professional translators at Cardiff University and translations verified by fertility experts in collaborating countries. We believe this was a rigorous process and the findings suggest the translation was valid (e.g. similarity of gender differences across countries, reliability, mean and SD) but as with all international research, constructs could be perfectly translated but not fully capture cultural elements of the concepts investigated (Bowden and Fox-Rushby, 2003). Over 100 000 people visited the website during the 9-month recruitment period but only 6.2% completed the survey. The survey software (SurveyTracker) was unable to record drop-out rates of those visitors who started the survey but did not complete it. As a result we cannot distinguish between visitors who did not meet the inclusion criteria and visitors who did not wish to participate or discontinued their participation. Future research using the Internet as a recruitment method needs to employ more sophisticated software to adequately assess uptake and response rates to such surveys. Additionally, Internet research can be compromised by the fact that people could have researched answers to our knowledge questions just before completing the survey. However, given a knowledge level of \sim 57% correct answers, it seems unlikely that this was a systematic source of error. Similarly, men and women were treated independently in our analyses but it is possible that they were spouses and we have no way of detecting this possibility. However, given that most variables showed significant gender differences we do not think that carrying out the more sensitive statistical tests for non-independence would have altered our conclusions about gender. The sample size was > 10000 which reduced error variation in the estimation of means and allowed for detection of small differences between groups (e.g. <5% knowledge difference in some comparisons). However, there is trade-off between this sensitivity and practical implications of the findings, and this trade-off needs to be considered when interpreting study findings, especially with regard to small effect sizes (r' < 0.10).

Conclusion

Overall the sample had a modest level of fertility knowledge and a positive and negative view of treatment. Knowledge and beliefs were determined by social background and fertility/infertility experiences. Recruitment methods were associated with volunteer bias (gender, personal relevance, education) but a replication of wellestablished gender differences and expected results in our study validated the methods used. The World Disability Survey identifies infertility as an impairment of function, which is fifth on the list of moderate-to-severe disabilities within the global population under the age of 60 years (World Bank and World Health Organization, 2010). Educational interventions should therefore be directed at improving knowledge of fertility health and at ensuring people have a realistic view of fertility treatment from the start. Future prospective research should be aimed at investigating how fertility knowledge and treatment beliefs affect fertility and making the decision to seek help. Future research should incorporate the use of both qualitative and quantitative population-based prospective designs following people over time to establish a better understanding of these processes and how they impact on fertility decision-making.

Supplementary data

Supplementary data are available at http://humrep.oxfordjournals.org/.

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Authors' roles

L.B. and J.B. contributed to the conception and design of the study, the acquisition of data and the analysis and interpretation of data. They drafted all versions of the article and approved the final version for publication. I.T. contributed to the conception and design of the study, acquisition of data, the revisions of each version and the approval of the final version for publication.

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Conflict of interest

The research was funded by a pharmaceutical company and I.T. is an employee of Merck-Serono S. A. Geneva-Switzerland (an affiliate of Merck KGaA Darmstadt, Germany).

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Appendix

Cardiff Fertility Knowledge Scale: fertility knowledge was assessed using a 13-item questionnaire (correct responses are underlined).

Instructions: below are some statements concerning fertility. Please indicate whether you believe the statements are TRUE or FALSE of fertility by ticking the appropriate box. If you do not know the answer please tick DON'T KNOW.

- (i) A woman is less fertile after the age of 36 years. <u>TRUE</u>/FALSE/DON'T KNOW
- (ii) A couple would be classified as infertile if they did not achieve a pregnancy after I year of regular sexual intercourse (without using contraception). TRUE/FALSE/DON'T KNOW
- (iii) Smoking decreases female fertility. <u>TRUE</u>/FALSE/DON'T KNOW
- (iv) Smoking decreases male fertility. TRUE/FALSE/DON'T KNOW
- (v) About 1 in 10 couples are infertile. <u>TRUE</u>/FALSE/DON'T KNOW
- (vi) If a man produces sperm he is fertile. TRUE/<u>FALSE</u>/DON'T KNOW
- (vii) These days a woman in her 40s has a similar chance of getting pregnant as a woman in her 30s. TRUE/FALSE/DON'T KNOW
- (viii) Having a healthy lifestyle makes you fertile. TRUE/<u>FALSE</u>/ DON'T KNOW
- (ix) If a man has had mumps after puberty he is more likely to later have a fertility problem. $\underline{\mathsf{TRUE}}/\mathsf{FALSE}/\mathsf{DON'T}$ KNOW
- (x) A woman who never menstruates is still fertile. TRUE/FALSE/DON'T KNOW
- (xi) If a woman is overweight by more than 2 stone (13 kg or 28 pounds) then she may not be able to get pregnant. TRUE/FALSE/DON'T KNOW
- (xii) If a man can achieve an erection then it is an indication that he is fertile. TRUE/FALSE/DON'T KNOW
- (xiii) People who have had a sexually transmitted disease are likely to have reduced fertility. TRUE/FALSE/DON'T KNOW